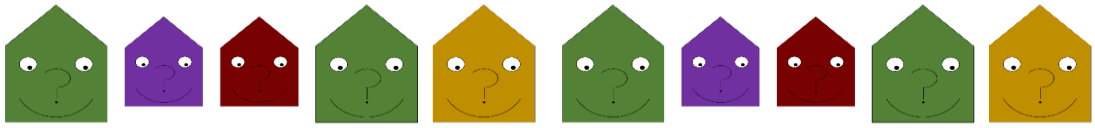

The impact of medical technology upon the home and feelings of at-homeness for children and young people with complex health care needs and their family members

Tracy Karen Mitchell

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Faculty of Health, Social Care and Medicine
Edge Hill University
Ormskirk

Declaration

This thesis is entirely my own work and has not been submitted, in full or in part for the award of a higher degree at any other educational institution. Sections of the thesis have been presented at conferences, disseminated via social media, or are under construction for publication. Details are listed below:

Oral Conference Presentations

Mitchell, T. K. (2019) Life at Home with Children & Young People's Medical Technology: The Findings of a Photo-Elicitation Interview Study. *Living Longer, Healthier & Happier PhD Symposium 2019*, Public Health Institute, Liverpool John Moores University. 26th July 2019.

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Mitchell, T.K. (2018) Life at Home with Children, Young People and Young Adult's Medical Equipment. Work in Progress: Lessons learnt from Engaging the Parents' Voice. *Partnership in Action: Overcoming Training Challenges to be Better at Home*. WellChild National Conference. Edge Hill University, Ormskirk. 3rd July 2018.

Mitchell, T. (2018) The Life at Home with Medical Equipment Study. *Work in Progress Session*, Faculty of Health and Social Care, Edge Hill University, Ormskirk. 12-1pm. 7th March 2018.

[1] Lyn Romeo, Chief Social Worker for Adults, Department of Health and Social Care shared a copy of the above presentation with Sir Terence Stephenson, Consultant Paediatric Doctor and Council Chair of the General Medical Council; Professor Ruth Gilbert, UCL Institute of Child Health; and Rachel Conner, Department of Health. As a result of hearing my presentation and how I had used AAC, Lyn Romeo and Ruth Allen (BASW) discussed amending the Social Work Professional Capabilities Framework to include the use of AAC.

Poster Conference Presentations

Mitchell, T.K., Carter, B., Blake, B., and Dickinson, A. (2018) Life at Home with Medical Technology: An Integrative Review. *HEI Service User & Carer leads in Health and Social Care Networking Forum*. Edge Hill University, Ormskirk. 19th June 2018.

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Knighting K., Bray L., Downing J., Kirkcaldy A., Mitchell T., O'Brien M.R., Pilkington, M., and Jack B.A. (2017) 'Children and Adult Hospice Provision for Young Adults with Life-Limiting Conditions: A UK survey'. *Hospice UK 2017 National Conference: Leading, Learning and Innovating*, ACC, Liverpool. 22nd-24th November 2017.

Mitchell, T., Carter, B., Bray, L., and Blake, L. (2017) 'Life at Home with Medical Technology – A Review of the Key Literature'. *No Place like Home. Challenges and Solutions.* WellChild Conference. Kings House Conference Centre, Manchester. 15th September 2017.

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Dedication

I dedicate this thesis to all children and young people with complex health care needs and their family members. Parents, I admire your strength and determination to ensure that your child receives the best care even though you are often physically and emotionally exhausted. I hope that the dissemination of findings from this study can positively inform the future planning, development and delivery of appropriate and effective technology and services. I hope that such technology and services are what you want, need and value, and they enhance your experiences of living at home with medical technology, and the health, wellbeing, quantity and quality of life of all your family members.

Glossary of Terms

Augmentative and Alternative Communication Device (with Brain-Computer Interface): Although not commonly considered as 'medical technology', augmentative and alternative communication (AAC) and other equipment such as brain–computer interface (BCI) enable children (or adults) to command devices, such as wheelchairs, using only eye gaze or brain signals.

Child: Although the legal definition of a child in the United Kingdom is a child who has not yet reached their 18th birthday, within this thesis, the term child will be used to describe a child, young person or adult who requires medical technology and is aged up to 25 years old. This is because children who have a disability can be provided with services to safeguard and promote their welfare under the Children Act 1989 until they are aged 25 years.

Complex Health Care Needs: The term complex health care needs generally indicates that a child has an irreversible life-limiting or life-threatening condition and is expected to die prematurely. They may also have a severe disability and special educational needs.

Family: The concept of family can be broad. Family, in the context of this study is the parent(s) and child/ren (related by blood ties or adopted) living together as a unit.

Home: Home, in the context of this study, is the physical domestic building where a child lives with their family and includes places such as the garden or garage.

Life-limiting conditions: The term life-limiting condition is used to describe diseases that cannot be cured and from which a child will die prematurely. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on their parents and carers.

Life-threatening conditions: Life-threatening conditions are those for which curative treatment may be feasible but can fail. Children in long-term remission or following successful curative treatment are not included in this definition.

Palliative Care: An active and total approach to care from the point of diagnosis or recognition through to death and beyond. Palliative care focuses on enhancement of quality of life for the child/young person and support for the family. It includes symptom management, the provision of short breaks and care through death and bereavement.

Technology-dependent: Although there is also no agreed definition for the term technology-dependence in the United Kingdom, within this thesis, technology-dependence refers to *medical* technology and equipment which is used to monitor and treat a child's medical condition(s), to maintain their health status, prevent further disability or to sustain their life.

Wellbeing: Wellbeing is having the physical, psychological, emotional, social, and spiritual resources to function well and meet challenges.

Young person: A generic term used in this study to describe adolescents and young adults up to the age of twenty-five years.

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Abstract

Background: The needs of technology-dependent children and young people with complex health care needs are complex and challenging. Although the home is generally the preferred and expected place of care, little is known about how the medical technology impacts the home and life at home for different members of a family.

Aim: To explore how medical technology impacts upon the home and life at home for children and young people with complex health care needs and their family members.

Methods: A qualitative study using face-to-face and telephone semi-structured or auto-driven photo-elicitation interview methods with a purposive sample of technology-dependent children aged 5-25 years and/or their family members. The interview transcripts were analysed interpretatively using thematic analysis.

Findings: Three themes were identified from the data: 1) Altered Physicality, Feeling and Meaning of Home, 2) The Presence of Carers in the Home, and 3) Home is not Home without their Child. The home and feelings of at-homeness were altered by living with technology. Families had little or no choice but to accept the extensions, adaptations and technology that altered the look, sound, feel and function of their home, and were not always involved in the extension and adaptation processes. The intrusion of paid carers and sounds from the technology and always being on call for their child created challenges for their home being a place of rest, relaxation and regeneration. Although the adaptations and technology often kept the children out of hospital and supported the families to live at home together, they also created barriers for leaving the home and for accessing other people's houses.

Conclusion: Families felt that the negative impacts of medical technology upon the home and life at home were worth it because their home was not home and their family was not complete without their child.

Ethical Considerations: Ethics approval was granted by the Edge Hill University Faculty of Health, Social Care and Medicine Research Ethics Committee.

Key Words: Children, medically fragile; Young Person; Young Adult; Complex Health Care Needs; Family; Medical Homes; At-homeness; Therapeutics; Equipment and Supplies; Biomedical Technology.

Chapter 1: Background

1.1 Introduction

The population of children and young people who have complex health care needs nationally and internationally has grown over the last 30 years (Together for Short Lives, 2016b, 2020a; Toly et al., 2017) as a result of advances in neonatal and intensive care, medical science, technology and clinical expertise (Kirk, 2010; Ling, 2012; Carter, Edwards and Hunt, 2015; Jarvis et al., 2016).

Although the legal definition of a child in the United Kingdom is a person who has not yet reached their 18th birthday, within this thesis, the term child will be used to describe a child, young person or adult who requires medical technology and is aged up to 25 years old. This is because children who have a disability can be provided with services to safeguard and promote their welfare under the Children Act 1989 (S17) until they are aged 25 years (at which point these services could be provided under the Care Act 2014 (or, in Scotland, the Social Care (Self-directed Support) (Scotland) Act 2013).

Complex health care needs is a term that generally indicates that a child has a life-limiting or life-threatening medical condition that cannot be cured and from which they will die prematurely (Fraser et al., 2012). The term life-limiting condition is used to 'describe diseases with no reasonable hope of cure that will ultimately be fatal' (i.e. the child is expected to die) (Fraser et al., 2012: 923). Some of these conditions cause progressive deterioration rendering a child increasingly dependent on parents and carers. Life-threatening conditions are those for which curative treatment may be feasible but can fail. Children in long-term remission or following successful curative treatment are not included in this definition. Complex health care needs is a term that might also be used to indicate that a child has a disability or special educational needs (Community Care, 2007). Other examples of terms that might be used to describe a child with complex health care needs are a child with serious health conditions (WellChild, 2018), complex care needs (Woodgate et al., 2015; Brenner et al., 2018), medically fragile (Rehm and Bradley, 2005a; Black, Holditch-Davis and Miles, 2009), medical complexity (Nageswaran and Golden, 2017), chronically ill (de Lima, de Paulo and Higarashi, 2015), exceptional needs (Kerr et al., 2014; Fraser et al., 2015) and complex medical needs (Elias, Murphy and the Council on Children with Disabilities, 2012; Edelstein et al., 2017).

Children who are technology-dependent are a small but growing (Gomez Mandic et al., 2017) subset of children with complex health care needs, and set apart by the high level and nature of their needs (Kirk, 1998, 1999) and the 'extraordinary quantity and quality of care' that they

require (Diehl et al., 1991: 170). There is no agreed definition for the term technology-dependence in the United Kingdom (UK) (Glendinning et al., 2001). Technology-dependence is a term that originated in America over thirty years ago but has been used increasingly in the UK (Kirk, 1999a; Kirk and Glendinning, 2004). Technology-dependence is a term that is used to describe children who require 'both a medical device to compensate for the [partial failure or] loss of a vital body function and substantial and ongoing [hospital level] nursing care to avert death or further disability' (U.S. Congress Office of Technology Assessment, 1987: 3). In the UK, the term technology-dependence generally indicates that equipment is used to diagnose, monitor and treat medical conditions and sustain life (Carnevale, 1991; Hewitt-Taylor, 2010; Wallis et al., 2011). It is necessary here to clarify that technology-dependence in the context of this study, refers to *medical* technology which maintains the child's health status (Eaton, 2008), prevents further disability or sustains their life (Nicholl et al., 2013; Carter, Edwards and Hunt, 2015).

The prevalence and complexity of need of children who have complex health care needs, and life-limiting/life-threatening conditions will be presented in this chapter. The drivers for home-based care and the implications of providing care at home for families of children who are technology dependent will also be presented.

1.2 Prevalence of Children who have Life-Limiting or Life-Threatening Conditions and who are dependent upon Medical Technology

The prevalence of babies, children and young people aged up to 19 years with life-limiting or life-threatening conditions in England has almost trebled between 2001/02 and 2017/18, from 32,975 in 2001/02 to 86,625 in 2017/18 (Together for Short Lives, 2020a). The number of children living with life-limiting or life-threatening conditions in 2018 was estimated to be 5,933 in Scotland; 3,650 in Wales; and 2,497 in Northern Ireland (Together for Short Lives, 2020a). Boys were significantly more likely to have life-limiting or life-threatening conditions than girls '(72.5 per 10,000 vs girls 60.0 per 10,000) in 2017/18, although there was no difference in the rise in prevalence between sexes over time' (Fraser et al., 2020: 10). Although the population of children with complex health care needs may appear relatively small compared to the populations of children facing other health challenges, this population is growing (Mitchell et al., 2016; Together for Short Lives 2016) with a projected increase of a further 11% to 97,242 by 2030 in England (Together for Short Lives, 2020). To put the prevalence figures into context, based on estimates from 2014 (Tickle, 2015; Together for Short Lives, 2016b), an average of two children in every school were living with life-limiting or life-threatening conditions and would die prematurely (before their parents) in 2018.

Current prevalence data to identify the number of children who are technology-dependent within the UK or internationally could not be found, despite conducting an extensive search. This may be because of the ambiguity in terms and definitions to describe this population (Glendinning et al., 2001; Spratling, 2015) and because accurate, comparable data were either unavailable or studies had been conducted utilising different datasets and coding frameworks, with children grouped into different age groups, whose conditions may have been defined differently and with not easily comparable time periods (Jones et al., 2002; Fraser et al., 2012, 2015; Noyes et al., 2013). Glendinning et al. (2001), who had used data from between 1994 and 2000[2] estimated that 6,000 children in the United Kingdom (UK) were dependent upon medical technology to monitor and treat their medical condition and sustain their life. This estimated figure has continued to be quoted by others (Department of Health, 2007) although this figure is now likely to be an underestimate. Other research shows that technology-dependence was estimated to have increased 10-30 fold between 1994 and 2010 (depending upon the type of technology) (Department of Health, 2007; Hewitt-Taylor, 2010; Wallis et al., 2011; Noyes et al., 2014), and the number of children on long-term ventilatory support almost doubled in the three years between 1997 and 2000, from 136 to 241 (Cejer, 2007), and then almost quadrupled to 933 in 2010 (Wallis et al., 2011). The population of children to which this study relates tend to rely on more than one item of technology for their survival or to prevent further disability. They are set apart from, for example, children with diabetes, epilepsy or asthma, who may require extensive care, but only minimal equipment, so do not tend to be categorised as technology-dependent in the literature (Kirk, 1998; Floriani, 2010).

1.3 Complexity of Need

Behind these prevalence figures are children who have survived rare congenital and metabolic disorders, critical illness, preterm birth, accidents or trauma (Lindahl and Lindblad, 2011; Mesman et al., 2013; Nicholl et al., 2013; Toly et al., 2017). Their substantial and long-term (Breneol et al., 2019) overlapping, round the clock (Marsh et al., 2011), unpredictable (Jarvis et al., 2016), varied, complex, and expensive (Hunt et al., 2013; Mitchell et al., 2016) medical and technological needs are typically met by their family within their home. The unpredictability of the children's disease trajectories is often linked to their condition being rare (Fraser et al., 2015:49), and their symptoms being so complex that a definitive diagnosis might not be given (Together for Short Lives, 2013). It is important to note that in addition to being technology-

[2] Family Fund Trust register and surveys, studies of specific clinical conditions or technology use, children's hospices use, local child health registers, and lastly, their own interview data with specialist hospital services and health purchasers.

dependent and having complex health care needs and life-threatening or life-limiting conditions, children may also have coexisting disabilities, developmental delays, special educational needs and may use augmentative and alternative communication devices[3] 'associated with speech, vision, hearing, or mobility impairments' (Spratling, 2015: 645). Some children are cognitively able. These factors add to the challenge of planning and meeting the needs of these children, who will often require palliative care[4].

Together for Short Lives (2013: 11) developed four broad categories which outline the four 'types of illness trajectory' that result in children requiring palliative care and dying prematurely. The illness trajectory of the children to whom this study relates are likely to be category 4 (Table 1.1).

Table 1.1 The Four Types of Illness Trajectory (Together for Short Lives, 2013: 11)

Category	
1	Life-threatening conditions for which curative treatment may be feasible but can fail (e.g. cancer, irreversible organ failures)
2	Conditions where premature death is inevitable (e.g. cystic fibrosis, Duchenne muscular dystrophy)
3	Progressive conditions without curative treatment options where treatment is exclusively palliative and often extends over many years (e.g. Batten disease, mucopolysaccharidoses)
4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death (e.g. severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, **complex health care needs**)

Managing the complex health care needs and any overlapping disability and/or special educational needs of this growing population of children at home (Mitchell et al., 2016; Hunt et al., 2013; Marie Curie Cancer Care 2012; Worldwide Palliative Care Alliance 2014), as well as the equipment and resources that are required for the child's physiological and technological needs (Murphy, 2008) can be extremely challenging and 'a significant

[3] Augmentative and alternative communication (AAC) and other equipment such as brain–computer interface (BCI) enable children and adults to 'command a device, such as a wheelchair' (Diez et al., 2013: 1155) or a 'computer to, for example, browse the internet, send emails or control lights or temperature in a room' (Townend et al., 2016: 101) using only [eye gaze or] brain signals and without any muscle movements' (Diez et al., 2013: 1155).

[4] Palliative care is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (Together for Short Lives, 2016a).

component of daily life' for families[5] who are caring for their child at home (Nicholl et al., 2013: 234). Despite these challenges, home is perceived by families and health and social care professionals to be the preferred place of care, and consequently, the place where most children with complex health care needs live.

1.4 The Drivers for Home-Based Care

Home-based care became the model of care in the late 1980's (Whiting, 2017). This section provides a brief context for why children with complex health care needs are now typically cared for by their parents in their family home, rather than in institutions (Glendinning et al., 2001; Elias, Murphy and the Council on Children with Disabilities, 2012) or hospital (Nicholl et al., 2013). Since the drivers for care and support are 'dependent upon societal values and priorities' (Jasper, 2003: 77) these will now be explored. The societal and legislative drivers for home-based care will be presented first and the financial drivers second.

The first drivers for home-based care were arguably societal and legislative. The Disabled People's Movement (1974) and Disabled People International (1981) lobbied to move away from the medical model of disability, which focuses on what the person cannot do, to a social model of disability, which considers that the person is disabled by prejudicial attitudes and by the lack of resources to be able to fully participate in social life (Thompson, 2018). Policies of deinstitutionalisation, such as the Disability Discrimination Act (1995), which was the UK's first anti-discrimination legislation for people who were disabled, and the National Health Service and Community Care Act (1990) began to emerge as a result of the Disabled People's Movement (1974) and Disabled People International's (1981) drive to overcome attitudinal, physical and organisational barriers to participation for people who are disabled.

Other legislation and guidance and the provision of rights for children with disabilities and their families then followed. Key legislation such as the Children Act (1989, 2004) (HM Government, 1989, 2004), the United Nations Convention on the Rights of the Child (UNICEF, 1989), and the Children and Families Act 2014 (Part 3; Sections 23, 25, 28, 31), and guidance such as Every Child Matters (HM Government, 2003) make provision for the care of children with complex health care needs. Initiatives such as 'Better Care, Better Lives' (Department of

[5] Family, in the context of this study, is the parent(s) and child/ren (related by blood ties or adopted) living together as a unit.

Health, 2008) and 'NHS at Home: Community Children's Nursing Services' (Department of Health, 2011) followed.

As a result of this legislation parents have a right to expect to receive accessible, individualised, high-quality preventative and treatment services (Nicholl 2015; Ministry of Health 2016) that enhance the safety, health, and wellbeing[6] of their family members. They have a right to have some control over their child's condition and to receive support to be able to deliver the complex care regimes required by their child at home (Alsaleh et al., 2014; Noyes et al., 2014). Children and families also have the right to a private and family life under Article 16 of the United Nations Convention on the Rights of the Child (UNICEF, 1989) and Article 8 of the Human Rights Act 1998 (HM Government, 1998).

As a result of these societal and legislative moves, community children's nursing services in the UK expanded significantly from 1988 (Whiting, 2017). These services became 'the bedrock of the pathways of care' (Department of Health, 2011: 3) in the homes of children and their families (Carter and Coad, 2009). These services aimed to meet parents' rights and expectations of providing care at home, where possible, for their children who have acute and short-term conditions, long-term conditions, disabilities, complex conditions and life-limiting or life-threatening illness, including children who require palliative and end of life care (Department of Health, 2011; Whiting, 2017; While and Dyson, 2000), and children who are dependent upon technology (Wallis et al., 2011; Whiting, 2017). Home-based care began to be perceived as the right option for children with complex health care needs because of the growing evidence that the children's social, emotional, psychological and physical well-being could be enhanced by being cared for at home (Noyes, Godfrey and Beecham, 2006; Department of Health, 2011; Cockett, 2012; WellChild, 2016).

National Service Frameworks (NSF) in England (Department of Health and the Department for Education and Skills (DH & DfES) 2004) were introduced to guide the delivery of funding, and to monitor and analyse the delivery of services for children with complex health care needs. One of the goals of NSF in the UK (DH & DfES 2004) was to reduce the burden and impact of medical conditions on children's and families' lives by providing high-quality care and support, so that children and their families can achieve their maximum potential health

[6] Wellbeing is having the physical, psychological, emotional, social, and spiritual resources to function well and meet challenges; balancing individual resources and challenges faced, and having more resources than challenges (World Health Organization, 1948; Dodge et al., 2012).

and wellbeing, educational and social outcomes (Alsaleh et al., 2014), and avoid a costly health and social care crisis point being reached. The NSF (DH & DfES 2004) were superseded by the National Framework for Children and Young People's Continuing Care (Department of Health, 2016), which despite also focussing on promoting and ensuring the delivery of coordinated, child-centred, safe and high quality care in a safe and appropriate environment (Broach, Clements and Read, 2016) increased the threshold for children and their families to access services and support. For example, a child requiring continuous low-level oxygen therapy or daily physiotherapy to maintain optimal respiratory function is only classed as having a moderate, rather than a high or severe level of need.

The second driver for home-based care relates to reducing the cost of care for this growing population of children (Cockett, 2012). Children who are dependent upon technology are a 'resource-intensive' (Breneol et al., 2019: 13), high cost subpopulation of children with complex health care needs (de Banate, Maypole and Sadof, 2019). Estimates vary in relation to the differences in costs between hospital-based and home-based care for children with complex health care needs with costs ranging from at least 3 times (Department of Health, 2011; Cockett, 2012) to 4.62 times (Noyes et al., 2006) more expensive to care for children with complex health care needs, with or without ventilator dependence, in hospital in England (on a high dependency or intensive care unit, due to the level of care required) than at home.

The rising costs of the care are borne by the National Health Service (NHS) (92% in 2006 in England) as well as social services, education, and voluntary and independent sectors (Noyes et al., 2006), and arguably by families who are caring for their child at home (de Banate et al., 2019). Care provision is largely dependent on finite capital and human resources (McDermid and Bagshaw, 2009). Shifting service delivery to support 'sustainable, high-quality, patient-centred' (Ministry of Health 2012: 55) home-based care, rather than delivery in hospital (Nicholl et al., 2013), is one way of containing escalating costs (Noyes et al., 2006) and reducing the cost of care and support provision (Carnevale et al., 2008; Hunt et al., 2013; Care Quality Commission, 2014). This is especially relevant given that currently the children often 'have a hospital stay of greater than 28 days each year' (Fraser et al., 2020: 10).

1.5 The Meaning of Home

As this thesis is focussed on the home, this next section will explore the meaning of home. Home is the place of interest for this study, given that this is the place where children with complex health care needs spend most of their time (Foundation for People with Learning Disabilities, 2014), being cared for by their parents or other family members. Home is also the place that families, health and social care professionals view as the best place of care for

children with complex health care needs (Cockett, 2012; Alsaleh et al., 2014; González et al., 2017). Home, in the context of this study, is the physical domestic building where children live with their family and includes external home-places (for example, the garden or the garage) accessed by the children or where the children's medical technology is stored.

The home is much more than a 'physical building' (Oxford University Press, 2016) or dwelling. Home is an important place and space of human intention (Andrews, 2003), action (Seamon, 2017), control (Cresswell, 2004) and lived experiences (Heidegger, 2013) 'that are unselfconsciously assumed to be appropriate, reasonable and accepted without question' (Seamon, 2017: 100). Home is not just the environment in which we live 'but a way of being-in-the-world' (Moore et al., 2013: 152), 'traditionally characterized by a particular set of purposes, events and social interactions' (Andrews, 2003: 244). Apart from being a physical setting, home for some people is the only place where they can feel and be themselves (The Home Project, 2015; Moodscope, 2017), doing what they want, when they want and how they want (The Home Project, 2015), or not doing anything at all (Årestedt et al., 2016), without being judged by people in the outside world (Gillis, 2002; Årestedt et al., 2016; Moodscope, 2017).

The home 'represents a multitude of meanings (such as personal identity, security and privacy)' (Williams, 2002: 142). It is a place that can both inform and be informed by our identity (Gillis, 2002), because the knowledge and feelings that are developed through everyday experiences of the physical spaces (Gieseking et al., 2014) around us contribute to our 'centre of meaning' (Cresswell, 2004: 24), status (Williams, 2002), self-worth (Lessing, 1984; Seamon, 2017) and personal identity (Gieseking et al., 2014; Seamon, 2017). Place and identity are inseparable, contributing to our sense of belonging (Massey, 1994; Woodgate, Edwards and Ripat, 2012; Årestedt et al., 2016), and 'rootedness' (Cresswell, 2004: 24). Place contributes to the formulation of our long-term social and psychological development and identity, affecting our ability to 'construct meaning, foster attachments, and mediate change' and influencing our 'social formations, cultural practices, and political actions' (Gieseking et al., 2014: online). Home is of vital importance, underpinning the very essence of people's past, present, and future life.

Although for many people home is a place that provides a sense of comfort, safety, security and stability (Massey, 1994; Seamon, 2017), for others, home can be an place of poverty (National Children's Bureau, 2016), fear, abuse and neglect (Manzo, 2003; Mallett, 2004) from which they wish to temporarily or permanently escape (Hancock and Gillen, 2007). Children

with disabilities, especially when they have limited communication or mobility, are far more prone to both poverty and abuse than typically developing children (Hall and Elliman, 2006).

Home is an important consideration for this study as research has shown that human beings are mutually entwined (Seamon 2016), and 'inseparably conjoined' with their environments (Buttimer, 1976: 288). Changes to the home environment can influence what happens in the other areas of a person's life (Bronfenbrenner, 1979; Howe, 2009).

Altering the landscape of the home (Moore et al., 2013) through, for example, making alterations to its physical structure and introducing medical technology and equipment into its space can medicalise the home (Moore et al., 2010; Nicholl et al., 2013; Carter, Edwards and Hunt, 2015) and can impact upon how the home and the individuals and family within that home function. Health and social care professionals, policymakers and other professionals, such as architects, need to understand the impact that the home, and changes to the home, can have upon the physical, emotional and psychological health (Buttimer, 1976; Moore et al., 2013; Barry et al., 2018) and wellbeing outcomes and quality of life (Seamon, 2017) for people whose homes are 'a place where healthcare is designed and provided' (Barry et al., 2018: 2). By incorporating new understanding into their practice (Barry et al., 2018: 2), health and social care professionals, policymakers and architects can better create optimal home environments that support the health and wellbeing needs (Mulkins, Eng and Verhoef, 2005) of this growing population of children and their families, as well as the professionals and carers who work within that environment.

1.6 Home: The Needs of Different Family Members

Behind every child with complex health care needs is a family, a home and a community. Families are vital for providing most of the extremely specialised and complex care and support that their technology-dependent child requires at home. Managing the technology, equipment and resources that are required for their child's technological needs can become a significant component of daily life for parents (Kirk and Glendinning, 2004; Nicholl et al., 2013; Mitchell et al., 2016) for months, years or decades (Toly, Musil and Carl, 2012b; Carter, Edwards and Hunt, 2015; Jarvis et al., 2016). Many parents live with the knowledge that their child will die prematurely (Together for Short Lives, 2016b; Currie and Szabo, 2019; Imperial-Perez and Heilemann, 2019). Although caring for a child who is technology-dependent can be rewarding and enriching (Carnevale et al., 2006), the demands of care can also be challenging, stressful and overwhelming (Cockett, 2012; Nicholl et al., 2013). Family members can see-saw between feeling distressed or enriched by caring for their child at home (Carnevale et al., 2006). This level of caring can have a positive and negative impact on all

aspects of health and wellbeing (including social and financial wellbeing), quality of life and family functioning for all the family members (Moore et al., 2010; Toly et al., 2019; Boss et al., 2020). The positive and negative impacts of caring for technology-dependent children are discussed in more depth in the literature review, findings and discussion chapters.

As seen in family systems theory, 'what one family member thinks, feels, says or does affects what other family members think, feel, say or do' (Howe, 2009: 110). Similarly, changes in any one of the individual family members' lives (Bronfenbrenner, 1979) can have a lifelong impact on all other levels of their life (Briggs et al., 2014). As such, it is understandable that living with a child who relies upon technology is a family affair (Toly et al., 2017) and that the intensity of the care needed for their child (Diehl, Moffitt and Wade, 1991) and the presence of technology in the home can impact upon 'each and every member of the family' (O'Brien, 2001: 18).

Although families require support to continue delivering home-based care to meet their child's needs (Kirk and Glendinning, 2002, 2004; Heaton et al., 2005; Dybwik et al., 2011), service development to support families has not kept pace with the medical and technological advances that have resulted in this population of children living longer (Kirk 2010). There is an urgent need to ensure that 'services are properly planned, funded and delivered to ensure that these children, and their families, can live life to the full' and make the most of every moment together (Together for Short Lives, 2020: online).

1.7 Conclusion

The increasing population of children who have extremely complex health and technological care needs and families caring for them at home have been discussed within this chapter. The reasons why home-based care became the model of care for the children in the late 1980's have been explored. It is important to consider the impact of technology upon the home and life at home because human beings are 'inseparably conjoined' with their home, and changes to the home can influence all aspects of health, wellbeing and quality of life for each and every person who lives in that home.

Chapter 2: Critical Integrative Review of the Literature

2.1 Introduction

The number of children with complex health care needs who are reliant upon medical technology is increasing nationally and internationally (Fraser et al., 2015; Jarvis et al., 2016; Together for Short Lives, 2020b). This is concerning because the specialised (Kirk & Glendinning 2004), unpredictable (Jarvis et al., 2016), varied, complex and intensive care that these children require to survive is primarily delivered (often into adulthood) in the family home by their parents. The integration of medical technology within the home has implications for these children and their families, as well as for health and social care professionals and practitioners who support this care at home (Murphy, 2008). As the environment can impact upon health (Buttimer, 1976; Lindahl, Sandman and Rasmussen, 2003; Moore et al., 2013) and wellbeing outcomes, and quality of life (Seamon, 2017), it is important to identify how medical technology impacts upon the home and life at home for children and their families. This review aims to address a key question related to the topic.

2.2 Aim of the Literature Review

The main aim of the integrative literature review was to answer the question of 'How does medical technology impact upon the home and life at home for technology-dependent children and their immediate and wider family?'

2.3 Literature Review Method

An integrative review is a 'specific review method that [synthesises and] summarises past empirical or theoretical literature to provide a more comprehensive understanding of a particular phenomenon or healthcare problem' (Broome, 2000: 231; Whittemore and Knafl, 2005: 546). Integrative reviews are a robust and established method (Cooper, 1998; Whittemore and Knafl, 2005; Virdun et al., 2015) and this approach was chosen over other review methods for two key reasons. Firstly, the integrative review method was the best approach to collect, analyse, combine and synthesise quantitative, qualitative and mixed method empirical studies and non-experimental[7] studies in a systematic way to develop an in-depth understanding of the topic (Cooper, 1998; Whittemore and Knafl, 2005; Virdun et al., 2015). Secondly, literature from other fields outside of health, for example, community care, sociology and social work, psychology and geography, were required to answer the literature

[7] For example, correlation, survey, or case study, and in the case of this review, meta-synthesis studies.

review question. Integrative literature reviews are appropriate for the synthesis of multi-disciplinary evidence.

The review will be presented in accordance with the five stages of an integrative literature review method: 1) Problem identification, 2) Literature search, 3) Data extraction and evaluation, 4) Data analysis, and 5) Literature review findings and presentation (Cooper, 1998; Whittemore and Knafl, 2005).

Stage 1: Problem Identification

An increasing number of technology-dependent children with complex health care needs, nationally and internationally, are being cared for by their family members at home (Jarvis et al., 2016; Fraser et al., 2020; Together for Short Lives, 2020a). Technology-dependent children and their family members require technology, services, and support that meet their needs to enable them to remain at home together. The problem that is the focus of this integrative review is the lack of knowledge and understanding about how medical technology impacts the home and life at home for technology-dependent children and their immediate and wider family. Having a better understanding of the needs of technology-dependent children and their families should guide the development of improved service delivery and practice (Marie Curie Cancer Care, 2012; Worldwide Palliative Care Alliance, 2014; Mitchell et al., 2016).

Stage 2: Literature Search

All stages of the literature search were carefully constructed to produce a robust search. The key concepts and keywords/search terms relevant to how medical technology impacts the home and life at home for children and their family members were identified using the Population, Concept, and Context (PCC) method proposed by the Joanna Briggs Institute (2015) (Figure 2.1).

Figure 2.1 Population, Concept, and Context (PCC) Method (The Joanna Briggs Institute, 2015)

PCC	Key Concept
Population	• Child* OR young person OR young adult with complex health care needs (aged up to 25 years) • Family of the above (i.e. mother, father, sibling, grandparent etc.)
Concept	• Medical Technology
Context	• Home

This method informed the eligibility criteria for inclusion into the integrative review, as shown below.

Inclusion Criteria

- The article must be in the English Language.
- The article must have been published between 1988 and 2020.
- The article must contain the following three key concepts:
    1. Population: Children, young people or adults with complex health care needs aged up to 25 years or their family members (The study or article must include the perspectives of technology-dependent children, young people or young adults and/or their immediate or wider family members about life at home with medical technology).
    2. Concept: Medical technology for children, young people or young adults.
    3. Context: Home (The study or article must be about providing care for technology-dependent infants, children, young people or young adults with complex health care needs in the home setting, not schools or hospital).
- The article can report research which is empirical or systematic/integrative/meta-synthesis reviews of empirical studies.

Exclusion Criteria:

- Articles that do not include the perspective of technology-dependent children and/or their family members i.e. articles that only include the perspectives of health, education or social care professionals or practitioners.
- Articles solely about information technology and assistive technology. Although these can support the children's health and wellbeing, they are not preventing further disability or sustaining life.

The PCC (The Joanna Briggs Institute, 2015) method also helped with the identification of search terms by supporting identification of the key search terms (Figure 2.2).

Figure 2.2 Key Concepts & Search Terms

Key Concept	Medical Technology	AND	Home	AND	Children	AND	Complex Healthcare Needs
Key Word Search Terms	Technology (major concept)		Home		Child*		“Complex Healthcare Needs”
	OR		OR		OR		OR
	medical technolog*		Community		infant*		“complex health care needs”
	OR		OR		OR		OR
	"medical technology"		“Medical Homes”		adolescen*		“complex care”
	OR				OR		OR
	"medical technologies"				teenager*		“special health care needs”
	OR				OR		OR
	medical equipment				“young adult”		“exceptional healthcare needs”
	OR						OR
	"medical equipment"						Condition-specific e.g. cerebral palsy
	OR						
MeSH terms	Equipment and Supplies				Child, medically fragile		
	OR						
	Biomedical Technology				THEN age filters only (applied due to low results of first two key search term combinations)		
	OR						
	Therapeutics (Specific medical technology comes under therapeutics)		(Home nursing comes under therapeutics)		Infant 1-23 months, Child 2-5 years, Child 6-12, Adolescent 13-18, (Young Adult 19-24 years where available, e.g. MEDLINE), Adults 19-44		

The key concepts and search terms were used individually and in combination with Boolean Operators[8] to search health, life sciences and psychology bibliographic databases and other internet sources (CINAHL, PubMed Central (which includes Ovid Medline), PsychINFO, Web of Science and Discover More) (Appendix 1). Searching with key concepts, keywords and MeSH terms allowed a broad range of empirical and meta-synthesis literature relevant to the literature review question to be located.

The Medical Subject Headings (MeSH)[9] terms 'Children, medically fragile' 'Equipment and Supplies', 'Biomedical Technology' and 'Therapeutics' were identified by reviewing the keywords and the index terms used by CINAHL and PubMed Central to describe the concepts and search terms of articles. Two main searches for this review were undertaken. The first occurred early within the PhD journey and was completed on 16th October 2017. The second search was completed on 12th May 2020. The first database search (CINAHL) was supported by an expert librarian.

Publication date search parameters for the first search in 2017 were 1st January 1988 to 16th October 2017, and for the second search in 2020 were 1st October 2017 to 12th May 2020. The rationale for the first publication date search parameter of 1st January 1988 onwards was that home-based care became the model of care in the late 1980's and that community children's nursing services expanded significantly from 1988 (Whiting, 2017). The rationale for the second search publication date search parameter of 1st October 2017 onwards was to ensure the inclusion of all articles published during the time frame in which I completed my PhD and to ensure that no papers were missed by the first literature search ending on 16th October 2017. The age parameters used for all searches were infant 1-23 months, child 2-5 years, child 6-12 years, adolescent 13-18 years, young adult 19-24 years (where available, e.g. MEDLINE), adult 19-44 years to include the young adults aged 19-25 years that could otherwise have been missed. Articles were also identified through hand searching, bibliographic database alert emails and Mendeley[10] alert emails. Although not essential to an integrative review, a PRISMA 2009 Flow Diagram (Moher et al., 2009) is presented below. This diagram presents the results from both literature searches in terms of data identification, screening, eligibility, and inclusion processes (Figure 2.3).

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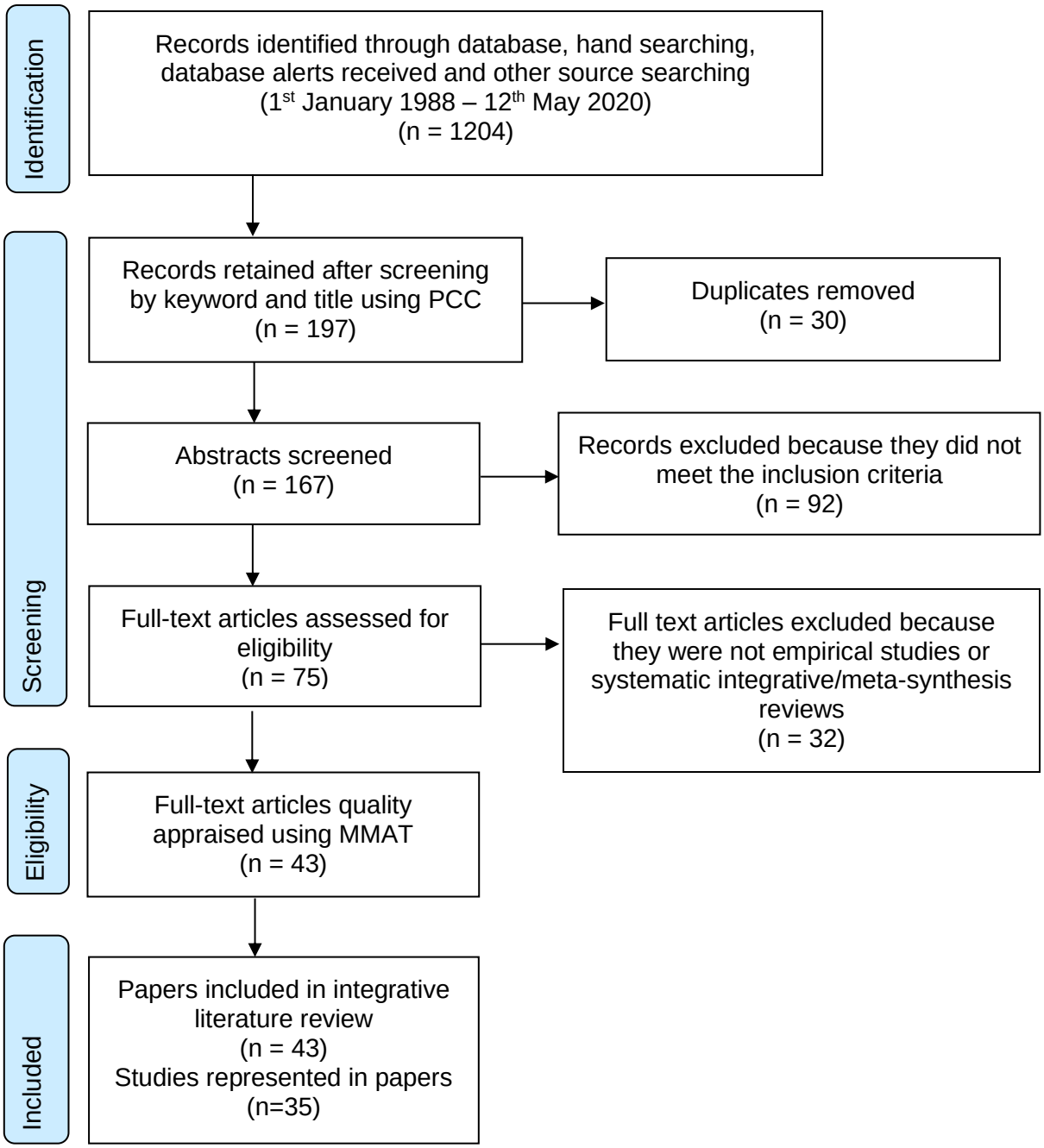
[8] Boolean Operators are words such as 'AND', 'OR', 'NOT' or 'AND NOT' used as conjunctions to combine or exclude keywords in a search, resulting in more focused and productive results.
[9] Medical subject headings (MeSH) are index (or controlled vocabulary thesaurus) terms used by the National Library of Medicine for their Medical Literature Analysis and Retrieval System Online (MEDLINE) and the PubMed databases to describe the content of the citation.
[10] A desktop and web programme used for managing articles and references.

Figure 2.3 PRISMA Diagram Showing Combined Results from both Literature Searches (Adapted from Moher et al., 2009)



Separate PRISMA 2009 Flow Diagrams (Moher et al., 2009) for the 2017 and 2020 searches are shown in Appendices 2 and 3.

Stage 3: Data Extraction and Evaluation

As shown in Figure 2.3, the combination of both searches resulted in 197 articles being retained for further appraisal. Thirty duplicate articles were removed, leaving 167 articles for further scrutiny. The abstracts of these 167 articles were then screened for the concepts of 'children, young people or (young) adults with complex health care needs' (or their family members), 'medical technology' or 'home'. If the key concepts were not explicit in the abstract, then the full article was screened. It became apparent that 92 articles did not meet the inclusion criteria, for example, they discussed the perspectives of health professionals or were not focussed enough upon medical technology and the home to answer the literature review question. Therefore, these articles were removed, leaving a total of 75 articles. Thirty-two articles that were neither empirical studies nor systematic, integrative or meta-synthesis reviews were discarded, leaving a total of 43 articles for inclusion into the integrative review. These 43 articles represented 35 studies - 33 empirical studies, one meta-synthesis (Lindahl and Lindblad, 2011) and one integrative review (Lindahl and Kirk, 2018) - because five papers reported data from one study (Kirk, 1999a, 2001; Kirk and Glendinning, 2002, 2004; Kirk, Glendinning and Callery, 2005) and five papers reported data from another study (Toly, Musil and Carl, 2012a, 2012b; Toly et al., 2017, 2019; Toly, Blanchette and Musil, 2019). Thirty two articles representing 25 studies and one meta-synthesis (Lindahl and Lindblad, 2011) were retrieved from the first literature search in 2017. The five Kirk et al. papers and three of Toly et al.'s papers (Toly, Musil and Carl, 2012a, 2012b; Toly et al., 2017) were retrieved in the 2017 literature search. A further 11 articles representing eight studies and one integrative review (Lindahl and Kirk, 2018) were retrieved from the second literature search in 2020. The remaining two Toly et al. papers were retrieved in the 2020 literature search (Toly et al., 2019; Toly, Blanchette and Musil, 2019).

I chose to critically appraise the quality of the articles included in this literature review for two key reasons: (1) to be able to describe the quality of the studies I included (Hong et al., 2018), and (2) 'to nuance the recommendations' (Hong et al., 2018: 286) according to the weight given to the included evidence according to its quality rating (see page 18 for details of scoring).

Conducting an objective evaluation and reflection of the quality of the articles included in this review aims to support 'decision makers to understand the transferability of the findings' (Majid

and Vanstone, 2018: 2115). It should also support readers to evaluate whether my conclusions are trustworthy (Hong et al., 2018).

The Mixed Methods Appraisal Tool (MMAT), version 11 (Pluye et al., 2011), was chosen to quality appraise the 41 articles representing primary empirical studies. A benefit of the MMAT is that it can be used to appraise and judge the methodological quality of qualitative, quantitative, and mixed-methods studies. Therefore, rather than choosing different critical appraisal tools for each of these study designs and having different appraisal criteria, the MMAT offers a more coherent approach. Another reason for selecting the MMAT is that it has been used in other relevant studies to appraise the literature, for example, McCann, Bull and Winzenberg's (2015) study about sleep deprivation in parents caring for children with complex health care needs at home. Using the MMAT (Pluye et al., 2011) aimed to reduce the likelihood of inaccuracy and bias, enhance rigour and present an accurate representation of the literature (Whittemore and Knafl, 2005). However, the MMAT (Pluye et al., 2011) is not designed to quality appraise review articles, so was not used for the two review articles (Lindahl and Lindblad's (2011) meta-synthesis and Lindahl and Kirk's (2018) integrative review). The scoring of the 41 articles based on primary empirical work was undertaken using a scoring system of 4-star, 3-star, 2-star, and 1-star. Articles scored 4-star when all quality criteria questions were ticked ‘yes’; 3-star was scored when 3 out of the 4 criteria were ticked ‘yes’; 2-star was scored when 2 out of the 4 criteria were ticked ‘yes’; and 1-star was scored when only one criterion was ticked ‘yes’. The scoring of these 41 primary empirical articles helped in being able to claim that evidence presented in my review was trustworthy. By trustworthy, I mean that the conclusions I have drawn can be depended upon as they are based on taking into account the quality of the individual articles and considering the poorer quality (e.g., 1-star and 2-star) evidence in the context of higher quality (3-star and 4-star) evidence. The quality scores of empirical articles are shown in Appendices 4 and 5.

The MMAT (Pluye et al., 2011) quality appraisal process revealed that only 17 out of 41 empirical papers (not including the meta-synthesis or integrative review) (41%) achieved the highest possible appraisal score of 4-star (Kirk, 2001; Lehoux, Saint-Arnaud and Richard, 2004; Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Toly, Musil and Carl, 2012a, 2012b; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Woodgate et al., 2015; Carter et al., 2018; Castor et al., 2018; Israelsson-Skogsberg et al., 2018; Imperial-Perez and Heilemann, 2019; Wilkinson, Bray, et al., 2020). MMAT scores can reflect the quality of reporting in the paper, rather than the actual methodological quality of the study as seen in the differing scores assigned for the same study in Kirk’s five papers (Kirk, 1999a, 2001; Kirk and Glendinning,

2002, 2004; Kirk, Glendinning and Callery, 2005) and Toly's five papers (Toly, Musil and Carl, 2012a; Toly et al., 2017, 2019; Toly, Blanchette and Musil, 2019) (Appendices 4 and 5).

Although MMAT scores can be subjective, a sample of the literature was independently appraised by three members of my supervisory team to ensure reliability of quality appraisal and, where necessary, discussion occurred until a consensus was achieved as suggested by Pluye et al. (2011). The results of the appraisal are presented in Appendices 4 and 5. Appendix 4 shows three quality synopses tables for the literature retrieved in 2017, and Appendix 5 show the quality synopsis table for the literature retrieved in 2020. To support the readability of the following literature review, the references will be presented in a smaller font than the main text as the number of references included is quite extensive in places and could be intrusive.

Stage 4: Data Analysis

All papers were imported into NVivo (QSR International, 2016). Each paper was read and reread and codes (known as nodes in NVivo) were created or added to in NVivo. The node hierarchy chart (generated at the end of the coding process) (Appendix 6) provides examples of codes. Lindahl and Lindblad's (2011) meta-synthesis study was examined last in 2017, to allow for independent interpretation, as six papers included in their study also met the inclusion criteria for, and thus, are included in this review (Wilson, Morse and Penrod, 1998; O'Brien, 2001; Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Earle et al., 2006). Lindahl and Kirk's (2018) integrative review was also examined last in 2020, to allow for independent interpretation, as one paper included in their study also met the inclusion criteria for, and thus, is included in this review (Dybwik et al., 2011). Overarching codes and sub-codes identified from the literature are presented in Table 2.3 below. The most frequent codes or sub-codes were easily identified from the coding process itself. However, as an additional check, I used the some of the features available in NVivo, such as the node hierarchy chart, the number of references and sources under the References and Source ribbons (Table 2.3), Word Frequency Query, and Text Search Criteria.

Table 2.3 Overarching Codes and Sub-Codes Identified in the Literature

Technology (Main Code)	No. of References	No. of Sources
Impact on Life (Sub-Code)		
Psychological or Emotional	152	35
Societal Attitudes	75	26
Financial	71	27
Social	67	31
Time	40	18
Sleep & Exhaustion	38	20
Physical	38	19
Normalisation	31	14
Getting Used To	25	13
Routine	25	10
Parent-Child Relationships	24	14
Couple Relationships	20	14
Privacy	19	14
Safety	10	8
Quality of Life	6	5
Impact on Child (Sub-Code)	53	16
Quality of Life/Prolonging Life	34	14
Psychological or Emotional	20	9
Social	17	7
Privacy	10	8
Child Voice	9	3
Normalisation	7	6
Child Choice	4	2
Spiritual	3	3
Types of Technology (Sub-Code)	73	20
Access to Technology (Sub-Code)	23	12
Family (Main Code)	**No. of References**	**No. of Sources**
Parent (Sub-Code)		
Role	106	31
Skills	86	24
Choice	43	15
Informational Needs	43	17
Concerns for The Future	23	14
Identity	4	4
Siblings (Sub-Code)	73	20
Support (Sub-Code)		
Family-Staff Relationship	60	22

Respite	17	12
Policy	14	10
Paid Carers/Professionals	12	9
Extended Family (Sub-Code)	23	12
Home (Main Code)	**No. of References**	**No. of Sources**
Effect of being at home (Sub-Code)	35	18
Reasons for getting home (Sub-Code)	34	16
Space (Sub-Code)	21	11
Adaptations (Sub-Code)	19	9
Barriers to getting home (Sub-Code)	13	9
Other Main Codes	**No. of References**	**No. of Sources**
Definitions	34	20
Key Words	33	33
Methods	84	31
Prevalence and co-morbidities	101	39
Rationale for study	14	9

Stage 5: Literature Review Findings and Presentation

This section of the chapter will present the findings of the review (Stage 5). A synthesis of the methods used in each article, the country where the article originated from, the terminology used to describe the children's health care conditions, and the study participants, is presented before organising the findings thematically to answer the question of 'How does medical technology impact upon the home and life at home for technology-dependent children and their family?'

The findings of this integrative review are based on 43 papers; 33 empirical studies, one meta-synthesis and one integrative review. A data extraction summary of the 43 articles that were reviewed was created (Appendix 7). Shaded rows are articles that were retrieved in the May 2020 literature search.

Twenty-six of the 33 empirical studies were qualitative. Most of the qualitative studies used semi-structured or in-depth interview methods and thematic analysis or constant comparison data analysis methods. Four studies were quantitative descriptive designs (Nicholl et al., 2013; Sakashita, Matthews and Yamamoto, 2013; Bourke-Taylor, Cotter and Stephan, 2014; Paddeu et al., 2015). Three studies (in 7 papers) used mixed methods (Heaton et al., 2005; Toly, Musil and Carl, 2012a; González et al., 2017; Toly et al., 2017, 2019; Toly, Blanchette and Musil, 2019). One paper was a meta-synthesis (Lindahl and Lindblad, 2011) and one was an integrative review (Lindahl and Kirk, 2018).

The studies were predominantly conducted in the United States of America (USA), Canada, and the United Kingdom (UK) and reflected different health care systems. Fifteen papers, representing eleven studies (the five Toly papers represent one study) were conducted in the USA (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Rehm and Bradley, 2005a; Black, Holditch-Davis and Miles, 2009; Toly, Musil and Carl, 2012b, 2012a; Sakashita, Matthews and Yamamoto, 2013; Gardner, 2014; Toly et al., 2017, 2019; Nageswaran and Golden, 2017; Toly, Blanchette and Musil, 2019; Imperial-Perez and Heilemann, 2019; Boss et al., 2020; Spratling and Lee, 2020). Seven studies were conducted in Canada (Wilson, Morse and Penrod, 1998; Lehoux, Saint-Arnaud and Richard, 2004; Levine, 2005; Carnevale et al., 2006; Earle et al., 2006; Woodgate et al., 2015; Currie and Szabo, 2019). Ten papers, representing six studies (the five Kirk papers represent one study) were conducted in the UK (Kirk, 1999a, 2001; Kirk and Glendinning, 2002, 2004; Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Hobson and Noyes, 2011; Samwell, 2012; Carter et al., 2018; Wilkinson, Bray, et al., 2020). Four studies were conducted in Sweden; one was identified in the literature search in 2017 (Lindahl and Lindblad, 2011) and three were identified in the literature search in 2020 (Castor et al., 2018; Israelsson-Skogsberg et al., 2018; Lindahl and Kirk, 2018). The other seven studies were conducted in Australia (Bourke-Taylor, Cotter and Stephan, 2014), Brazil (de Lima, de Paulo and Higarashi, 2015), Norway (Dybwik et al., 2011), Spain (González et al., 2017), Ireland (Nicholl et al., 2013), Japan (Nishigaki et al., 2016) and Italy (Paddeu et al., 2015).

As shown in the summary of the 43 articles (Appendix 7), the children who were the focus of the studies were described as having complex care needs (Bourke-Taylor, Cotter and Stephan, 2014; Woodgate et al., 2015), complex health care needs (Kirk, 1999a; Glendinning et al., 2001; Kirk and Glendinning, 2002, 2004; Kirk, Glendinning and Callery, 2005; Hobson and Noyes, 2011; Gardner, 2014; Carter et al., 2018; Wilkinson, Bray, et al., 2020) and specialised health care needs (Sakashita, Matthews and Yamamoto, 2013), and as being medically fragile (Wilson, Morse and Penrod, 1998; Rehm and Bradley, 2005a; Black, Holditch-Davis and Miles, 2009; Lindahl and Lindblad, 2011; Gardner, 2014), medically complex (Diehl, Moffitt and Wade, 1991; Nageswaran and Golden, 2017; Boss et al., 2020), or chronically ill (de Lima, de Paulo and Higarashi, 2015). Some children who were the focus of the studies were reported as having intellectual disabilities (Nicholl et al., 2013), developmental delay (Rehm and Bradley, 2005a; Carnevale et al., 2006) or regression (Lindahl and Lindblad, 2011; Boss et al., 2020), rare neurodevelopmental diseases (Currie and Szabo, 2019), and/or physical disabilities (Bourke-Taylor, Cotter and Stephan, 2014), showing a variation in cognition, development and mobility. The children were described as having chronic conditions (Lehoux, Saint-Arnaud and Richard, 2004; Dybwik et al., 2011; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011; Spratling and Lee, 2020), such as respiratory (lung) disease or failure (Wilson, Morse and Penrod, 1998; Earle et al., 2006; Sakashita, Matthews and Yamamoto, 2013; Woodgate et al., 2015; Carter et al., 2018; Castor et al., 2018; Israelsson-Skogsberg et al., 2018; Imperial-Perez and Heilemann, 2019; Spratling and Lee, 2020), such as congenital central hypoventilation syndrome (CCHS) (Carnevale et al., 2006; Earle et al., 2006; Lindahl and Lindblad, 2011; Paddeu et al., 2015; González et al., 2017; Israelsson-Skogsberg et al., 2018; Lindahl and Kirk, 2018); neurological diseases and conditions (Paddeu et al., 2015; Woodgate et al., 2015; Nageswaran and Golden, 2017; Toly et al., 2017; Israelsson-Skogsberg et al., 2018; Currie and Szabo, 2019), such as cerebral palsy (Heaton et al., 2005; Rehm and Bradley, 2005a; Toly, Musil and Carl, 2012a;

Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Gardner, 2014; Woodgate et al., 2015; Nishigaki et al., 2016; Spratling and Lee, 2020; Wilkinson, Bray, et al., 2020) or hydrocephalus (Rehm and Bradley, 2005a; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015); heart disease or conditions (Lehoux, Saint-Arnaud and Richard, 2004; Sakashita, Matthews and Yamamoto, 2013; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Castor et al., 2018; Spratling and Lee, 2020); cancer, congenital hiatal hernia, and Lyme disease (Castor et al., 2018). Some children required carers to be constantly vigilant for 24-hours a day because of their health conditions. Some children were highly dependent upon several types and pieces of technology continuously for 24-hours a day, whilst others might only require one type or piece of technology, for only a few minutes a day, or at night during sleep.

Only nine of the 33 empirical studies (27%) involved technology-dependent children as study participants (Kirk, 1999a; Lehoux, Saint-Arnaud and Richard, 2004; Heaton et al., 2005; Levine, 2005; Carnevale et al., 2006; Earle et al., 2006; González et al., 2017; Castor et al., 2018; Israelsson-Skogsberg et al., 2018). Approximately 79 technology-dependent children or young people (reporting of numbers was not clear in all studies) took part in these nine studies.

Only four of the 33 empirical studies (12%) involved siblings as study participants (Heaton et al., 2005; Levine, 2005; Carnevale et al., 2006; Castor et al., 2018). Approximately 46 siblings (reporting of numbers is unclear in the Levine study) took part in these four studies.

Thirty one out of the 33 empirical studies (94%) involved mothers and/or fathers as study participants: studies by Earle et al. (2006) and Israelsson-Skogsberg et al. (2018) did not, as their studies explored the experiences of home mechanical ventilation with children. As is typical in studies researching issues for children with complex health care needs or disabilities, 30 studies (91%) included mothers: studies by Israelsson-Skogsberg et al. (2018); Hobson and Noyes (2011) and Earle et al. (2006) did not include mothers. However, 19 of the 33 empirical studies (56%) involved fathers (Diehl, Moffitt and Wade, 1991; Kirk, 1999a, 2001; O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Kirk, Glendinning and Callery, 2005; Levine, 2005; Rehm and Bradley, 2005a; Heaton et al., 2005; Carnevale et al., 2006; Hobson and Noyes, 2011; Dybwik et al., 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Paddeu et al., 2015; Woodgate et al., 2015; Nageswaran and Golden, 2017; González et al., 2017; Carter et al., 2018; Castor et al., 2018; Currie and Szabo, 2019; Boss et al., 2020).

Only two of the 33 empirical studies (6%) included the perspectives of grandparents, representing only 2 grandmothers in total (Heaton et al., 2005; de Lima, de Paulo and Higarashi, 2015). This demonstrates a paucity of literature and a gap in the knowledge about the impact of medical technology upon life at home for extended family members. Only four studies (12%) included different members of the same family as study participants, for example, technology-

dependent children, their sibling(s) and parents (Heaton et al., 2005; Levine, 2005; Carnevale et al., 2006; Castor et al., 2018).

Three overarching themes are presented in the next part of the review: 'Parents are not Involved in Decision Making to Care for their Child at Home'; 'Technology has both Positive and Negative Impacts upon Family Members'; and 'Respite Needs'. The first theme to be presented is 'Parents are not Involved in Decision Making to Care for their Child at Home'.

2.4 Theme One: Parents are Not Involved in Decision Making to Care for their Child at Home

This section presents parental decision making about taking their child with medical technology home within three sub themes: 'Parents' Information Needs', 'Parental Thoughts and Feelings', and 'Parental Choice'.

2.4.1 Parents' Information Needs

The literature from England, Canada, Norway, the USA, Brazil, and Spain reports that professionals expect parents to care for their child at home (Kirk, 2001; Kirk and Glendinning, 2004; Carnevale et al., 2006; Dybwik et al., 2011; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Woodgate et al., 2015; González et al., 2017). However, despite this expectation, parents are not always included by professionals in decisions about their child's care and are not always part of decisions about caring for their child at home (Dybwik et al., 2011; Gardner, 2014; Woodgate et al., 2015; González et al., 2017). Open negotiations and explicit discussions between professionals and parents about the extent and quality of care that the children will require at home do not always occur (Kirk, 2001; Kirk and Glendinning, 2004). This can result in parents not knowing what to expect when they are living at home with their child, how to deal with their child's diagnosis and prognosis, how to manage their child's technology and service provision, and how demanding it will be to care for their child at home (Diehl, Moffitt and Wade, 1991). Parents do not anticipate the type of parenting experience that they will have with their technology-dependent child (Levine, 2005), nor the intensity of the roles that they will have to undertake in addition to their parenting role once their child comes home (Carnevale et al., 2006; Woodgate et al., 2015). Thus, parents may make naïve and hasty decisions about taking their child home (Levine, 2005; Carnevale et al., 2006; Gardner, 2014) when they are in environments, such as the hospital, where there can be an imbalance of power between the parents and professionals (Kirk, 2001).

2.4.2 Parental Thoughts and Feelings

In cases where parents are fully informed about the challenges that they will face in caring for their child at home, they are still unlikely to choose otherwise. Parents report that it is part of

their parental responsibility to care for their child at home (Kirk and Glendinning, 2004; Carnevale et al., 2006) and this reflects their devotion to their child (Lindahl and Lindblad, 2011). Most parents want to include their child in family life at home with them (Kirk and Glendinning, 2004). Home is the place where they and their child can feel comfortable, empowered (Bourke-Taylor, Cotter and Stephan, 2014; de Lima, de Paulo and Higarashi, 2015) and their child is socially stimulated (González et al., 2017) compared to more barren environments such as hospital. Studies show that being at home requires parents to sacrifice their own emotional wellbeing and quality of life for the sake of their child (Dybwik et al., 2011; Paddeu et al., 2015; Woodgate et al., 2015; González et al., 2017).

2.4.3 Parental Choice

Studies conducted in the USA (Imperial-Perez and Heilemann, 2019), Canada (Carnevale et al., 2006) and England (Kirk, 2001) report that parental decisions to care for their child at home are likely to be influenced by the fact that the only realistic alternative choice to home-based care for technology-dependent children is continued hospitalisation. There are few or no Local Authority (Kirk, 2001) or institutional care (Carnevale et al., 2006) environments that can provide care for children with specialised and complex medical and technological needs. Parents can neither give up on their child nor choose to let them die (Carnevale et al., 2006; Dybwik et al., 2011; Gardner, 2014) so they do not really have any other choice but to care for their child at home. One study reported that most parents report no regrets in choosing to care for their child at home (Carnevale et al., 2006).

Although the above sections addressing parents' information needs and parental thoughts and feelings include research evidence from poor quality articles (from empirical studies) (Levine, 2005; Paddeu et al., 2015; González et al., 2017), the evidence throughout Theme 1 is trustworthy. The trustworthiness of the findings occurs because the evidence from the articles weighted as 1-star (Levine, 2005; González et al., 2017) or 2-star (Paddeu et al., 2015) was only used in conjunction with evidence from articles weighted as 4-star (Kirk, 2001; Kirk and Glendinning, 2004; Carnevale et al., 2006; Dybwik et al., 2011; Bourke-Taylor, Cotter and Stephan, 2014; Woodgate et al., 2015; Imperial-Perez and Heilemann, 2019) or 3-star (Gardner, 2014; de Lima, de Paulo and Higarashi, 2015).

In summary, this section of the review reveals that parents are unlikely to predict the full impact that taking their child home from hospital will have upon their home and life. Their desire for their child to be at home and the lack of alternative places of care leaves them little choice. However, prior to discharging a child from hospital, changes to the home are likely to be necessary and these will be discussed within the second theme of 'Technology has both Positive and Negative Impacts upon Family Members'.

2.5 Theme Two: Technology has both Positive and Negative Impacts upon Family Members

The theme of 'Technology has both Positive and Negative Impacts upon Family Members' has six sub-themes: 'Types of Technology and Equipment'; 'Altering the Home and use of Spaces in the Home'; 'The Impact of Living with Technology for Technology-Dependent Children'; 'The Impact of Living with Technology on Siblings'; 'The Impact of Living with Technology on Parents' and 'The Impact of Living with Technology on Extended Family'.

2.5.1 Types of Technology and Equipment

This section of the review presents the wide range of specialised and standard medical technology, equipment, and consumables which are reported as being used to maintain children's health and wellbeing or prevent further illness or disability. The types of technology and equipment can be categorised according to purpose, and analysis of the studies revealed 13 major categories of technology and equipment (Table 2.4) that support the children's key physiological functions, well-being, communication and mobilisation or transportation.

Table 2.4 Types of Technology and Equipment

Respiratory Equipment	
High-tech devices (e.g. tracheostomies)	Wilson, Morse and Penrod, 1998; Carnevale et al., 2006; Earle et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011; Samwell, 2012; Nicholl et al., 2013; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Paddeu et al., 2015; Toly et al., 2017, 2019; Israelsson-Skogsberg et al., 2018; Spratling and Lee, 2020.
Long-term mechanical ventilators	Wilson, Morse and Penrod, 1998; Kirk, 1999a; Kirk and Glendinning, 2002, 2004; Levine, 2005; Carnevale et al., 2006; Earle et al., 2006; Dybwik et al., 2011; Samwell, 2012; Toly, Musil and Carl, 2012a; Nicholl et al., 2013; Paddeu et al., 2015; Toly et al., 2017; González et al., 2017; Carter et al., 2018; Lindahl and Kirk, 2018; Israelsson-Skogsberg et al., 2018; Toly, Blanchette and Musil, 2019; Spratling and Lee, 2020; Wilkinson et al., 2020.
Continuous positive airway pressure; bilevel positive airway pressure	Kirk and Glendinning, 2004; Heaton et al., 2005; Carnevale et al., 2006; Earle et al., 2006; Hobson and Noyes, 2011; de Lima, de Paulo and Higarashi, 2015; Spratling and Lee, 2020.
Oxygen therapy	Wilson, Morse and Penrod, 1998; Heaton et al., 2005; Lindahl and Lindblad, 2011; Toly, Musil and Carl, 2012a; Nicholl et al., 2013; Gardner, 2014; Paddeu et al., 2015; Israelsson-Skogsberg et al., 2018; Toly et al., 2019; Wilkinson et al., 2020.
Suction	Kirk, 1999a; Heaton et al., 2005; Earle et al., 2006; Dybwik et al., 2011; Lindahl and Lindblad, 2011; Nicholl et al., 2013; Gardner, 2014; Carter et al., 2018.
Inhalers and nebulisers	Nicholl et al., 2013; Gardner, 2014; Israelsson-Skogsberg et al., 2018; Spratling and Lee, 2020.
Cough assist	Dybwik et al., 2011; Spratling and Lee, 2020; Wilkinson et al., 2020.
Monitoring devices (e.g. cardio-respiratory monitor, oxygen saturation monitor or pulse oximeters)	Nicholl et al., 2013; Gardner, 2014; Paddeu et al., 2015; Imperial-Perez and Heilemann, 2019; Wilkinson et al., 2020.
Eating and Drinking Equipment	
Gastrostomies, percutaneous endoscopic gastrostomy (PEG) feeding equipment	Heaton et al., 2005; Nicholl et al., 2013; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Carter et al., 2018; Israelsson-Skogsberg et al., 2018; Toly et al., 2019; Spratling and Lee, 2020.

Enteral feeding	Earle et al., 2006; Hobson and Noyes, 2011; Nicholl et al., 2013.
Nasogastric, nasojejunal or jejunal tubes	Toly, Musil and Carl, 2012a; Gardner, 2014; Israelsson-Skogsberg et al., 2018; Imperial-Perez and Heilemann, 2019; Toly, Blanchette and Musil, 2019; Spratling and Lee, 2020.
Intravenous catheter such as total parenteral nutrition	Kirk, 1999a; Hobson and Noyes, 2011; Nicholl et al., 2013; Toly et al., 2017; Israelsson-Skogsberg et al., 2018.
Feeding pump	Nicholl et al., 2013; Gardner, 2014; Imperial-Perez and Heilemann, 2019.
Special diet or thickened feeds	Nicholl et al., 2013.
Adapted, customised or specialist dining table/tables or seating	Carnevale et al., 2006; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Cups, bottles or feeders, adapted cutlery, plates or nonslip mats	Nicholl et al., 2013: 233.
Protective clothing	Nicholl et al., 2013.
Liquidiser	Nicholl et al., 2013.
Toileting, Bathing and Dressing Equipment	
Toileting, bathing and dressing	Bourke-Taylor, Cotter and Stephan, 2014.
Enteral & bladder catheterization	de Lima et al., 2015.
Renal dialysis / peritoneal dialysis	Kirk and Glendinning, 2002; Heaton et al., 2005; Nicholl et al., 2013.
Colostomy (which is low-tech)	Kirk and Glendinning, 2004.
Enemas and suppositories	Nicholl et al., 2013.
Potty, seating and risers	Nicholl et al., 2013.
Nappies and pads (for children well above an age where they are usually used, i.e. children aged over 5 years)	Nicholl et al., 2013.
Mobilisation and Standing Equipment	
Equipment for mobilisation and standing (can be specialised & standard)	Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Wheelchairs (might have posture support)	Carnevale et al., 2006; Earle et al., 2006; Dybwik et al., 2011; Lindahl and Lindblad, 2011; Nicholl et al., 2013; Israelsson-Skogsberg et al., 2018.
Buggies	Nicholl et al., 2013.
Harnesses and straps for these	Nicholl et al., 2013.
Standing frame or bar	Nicholl et al., 2013.
Walker	Nicholl et al., 2013.
Hoist	Nicholl et al., 2013.
Splints and orthotics	Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Shoe/boot adaptions	Nicholl et al., 2013.
Supportive brace or cast	Nicholl et al., 2013.
Balance devices	Nicholl et al., 2013.

Sleeping Equipment	
Equipment for sleeping	Bourke-Taylor, Cotter and Stephan, 2014.
Adapted or special bed or cot, mattress and/or side rails	Lindahl and Lindblad, 2011; Nicholl et al., 2013.
Sleep system	Nicholl et al., 2013.
Monitoring devices such as an apnoea monitor	Nicholl et al., 2013.
Video monitor and baby monitors (even when the children are older)	Nicholl et al., 2013.
Waterproof bedding	Nicholl et al., 2013.
Specialist Equipment for Seating	
Adapted or specialist seating (for use inside and outside of the home)	Carnevale et al., 2006; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Positioning equipment	Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Posture supporting chairs	Nicholl et al., 2013.
Medical and Health Technology	
Medical and health technology	Earle et al., 2006; Bourke-Taylor, Cotter and Stephan, 2014; Wilkinson et al., 2020.
Intravenous drugs	Kirk and Glendinning, 2002; Dybwik et al., 2011; Hobson and Noyes, 2011; Gardner, 2014; Toly et al., 2017; Carter et al., 2018; Wilkinson et al., 2020.
Tablet crushers	Nicholl et al., 2013.
Drip Stands	Wilkinson et al., 2020.
Safety Equipment	
Sharps box for needles and sharps	Nicholl et al., 2013.
Stair gates	Nicholl et al., 2013.
Fireguards	Nicholl et al., 2013.
Window locks	Nicholl et al., 2013.
Cupboard locks	Nicholl et al., 2013.
Storage boxes and cupboards	Nicholl et al., 2013.
Communication Technology and Equipment	
Technology or equipment for communication	Dybwik et al., 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Communication devices (AAC: voice, eye or touch activated)	Nicholl et al., 2013.
Picture Exchange Communication Systems (PECS)	Nicholl et al., 2013.
Flash cards	Nicholl et al., 2013.
Laptops	Nicholl et al., 2013.
Hearing Aids	Nicholl et al., 2013.
Cochlear implant	Nicholl et al., 2013.

Glasses	Nicholl et al., 2013.
Play and Leisure Equipment	
Play and leisure equipment such as adapted toys and leisure Items	Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Multisensory equipment	Nicholl et al., 2013.
Playmats or gyms	Nicholl et al., 2013.
Consumables	
Gastrostomy tubes	Kirk, 1999a; Gardner, 2014.
Syringes	Kirk, 1999a; Nicholl et al., 2013; Wilkinson et al., 2020.
Suction catheters	Kirk, 1999a.
Oxygen masks and nasal prongs	Nicholl et al., 2013; Israelsson-Skogsberg et al., 2018.
Batteries	Nicholl et al., 2013.
Extension cables	Nicholl et al., 2013.
Gloves	Nicholl et al., 2013.
Medication	Kirk, 1999a; Gardner, 2014.
Dressings and tapes	Nicholl et al., 2013; Carter et al., 2018.
Tracheostomy tubes	Israelsson-Skogsberg et al., 2018.
Specialised Therapies and Equipment	
Physiotherapy	Nicholl et al., 2013; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Toly, Blanchette and Musil, 2019; Spratling and Lee, 2020.
Speech therapy	Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Spratling and Lee, 2020.
Occupational therapy	Nicholl et al., 2013; Gardner, 2014; Toly, Blanchette and Musil, 2019; Spratling and Lee, 2020.
Exercise ball	Nicholl et al., 2013.
Car or Van Modifications	
Ramp	Nicholl et al., 2013.
Specialised seating	Earle et al., 2006; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014.
Harnesses and straps	Nicholl et al., 2013.

Technology-dependent children often require large and expensive health technology (e.g. ventilators) and equipment (e.g. wheelchairs), as well as technology consumables (e.g. tracheostomy tubes) and medication (Kirk and Glendinning, 2004). A study by Nicholl (2013) found that technology-dependent children require an average of 22 pieces of equipment. The technology can be high-level or low-level technology. An example of high-level technology is breathing equipment (e.g. ventilator) (de Lima et al., 2015; Hobson and Noyes, 2011; Nicholl et al., 2013; Toly et al., 2017; Lindahl and Lindblad, 2011), whilst an example of low-level equipment is toileting equipment (e.g. adaptation to toilet seat) (Nicholl et al., 2013).

It is important to note that many technology-dependent children require multiple pieces of technology (Earle et al., 2006; Lindahl and Lindblad, 2011) and that the use of each piece of technology can be ongoing, intermittent or in reserve for emergencies, used only occasionally or for a few minutes a day or for 24 hours a day. The equipment might need changing or adding to as a

child grows and develops (Nicholl et al., 2013), or when it wears out. Obtaining the technology and equipment (Diehl, Moffitt and Wade, 1991; Carnevale et al., 2006), and the correct technology and size of technology (Diehl, Moffitt and Wade, 1991) can take years (Diehl, Moffitt and Wade, 1991; Carnevale et al., 2006).

The equipment type afforded the most attention by the greatest number of studies (n=23) was respiratory equipment (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998; Kirk, 1999a; Kirk and Glendinning, 2002, 2004; Levine, 2005; Heaton et al., 2005; Carnevale et al., 2006; Earle et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Hobson and Noyes, 2011; Samwell, 2012; Toly, Musil and Carl, 2012a; Nicholl et al., 2013; Gardner, 2014; Paddeu et al., 2015; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017, 2019; González et al., 2017; Carter et al., 2018; Israelsson-Skogsberg et al., 2018; Lindahl and Kirk, 2018; Imperial-Perez and Heilemann, 2019; Toly, Blanchette and Musil, 2019; Spratling and Lee, 2020; Wilkinson, Bray, et al., 2020). Most of these studies (n=16) focused on children who required high-level technology, such as ventilators (Wilson, Morse and Penrod, 1998; Kirk, 1999a; Kirk and Glendinning, 2002, 2004; Levine, 2005; Carnevale et al., 2006; Earle et al., 2006; Dybwik et al., 2011; Samwell, 2012; Toly, Musil and Carl, 2012a; Nicholl et al., 2013; Paddeu et al., 2015; Toly et al., 2017; González et al., 2017; Carter et al., 2018; Lindahl and Kirk, 2018; Israelsson-Skogsberg et al., 2018; Toly, Blanchette and Musil, 2019; Spratling and Lee, 2020; Wilkinson et al., 2020).

Evidence on the types of technology and equipment is trustworthy as it comes from 4-star (Kirk and Glendinning, 2004; Carnevale et al., 2006; Earle et al., 2006; Hobson and Noyes, 2011; Nicholl et al., 2013) and 3-star articles (from empirical studies) (Diehl, Moffitt and Wade, 1991; de Lima, de Paulo and Higarashi, 2015).

Nicholl et al. (2013) and Bourke-Taylor, Cotter and Stephan's (2014) quantitative descriptive studies and Dybwik et al.'s (2011) qualitative study were the only studies to report on the communication, play and leisure technology or equipment, as well as medical technology. Although this may have been a result of my eligibility criteria for inclusion into the integrative review or because when parents are asked to list the technology required by their child, they may forget to list communication devices, due to them having their child's life-saving technology at the forefront of their minds (Kirk and Glendinning, 2002; Heaton et al., 2005; Earle et al., 2006; Hobson and Noyes, 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017), these technologies or equipment, despite not necessarily keeping the children alive, are vital for enhancing their health and wellbeing and enabling them to participate in everyday life.

2.5.2 Altering the Home and use of Spaces within the Home

The impact of medical technology on the home was the aspect that had the least attention afforded in the literature, despite discussion in some papers about adaptations to the home and the altered use of spaces within the home. These are now discussed.

Although core to the literature search, only nineteen studies discussed the adaptations that had been made to the homes of technology-dependent children (O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Levine, 2005; Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Earle et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Samwell, 2012; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Paddeu et al., 2015; Woodgate et al., 2015; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017; Lindahl and Kirk, 2018; Carter et al., 2018; Wilkinson, Bray, et al., 2020). These studies were conducted in England, Ireland, Scotland, Italy, Sweden, Norway, Canada, Australia, Brazil, and the USA demonstrating that adaptations to the home are an international issue.

Some studies report that adaptations or extensions to the physical structure of the home or to the rooms within the home are often necessary before children with complex health care needs can go home from hospital (Lindahl and Lindblad, 2011; Samwell, 2012; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; de Lima, de Paulo and Higarashi, 2015; Lindahl and Kirk, 2018). Examples include purpose-built bathrooms or wet rooms and/or a child's bedroom created in a purpose-built structure or extension to the home, or in rooms that were used for alternative purposes before (such as the family lounge) (Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011; de Lima, de Paulo and Higarashi, 2015). Other adaptations to the home include having lifts and tracking for hoists fitted (Carnevale et al., 2006; Earle et al., 2006; Lindahl and Lindblad, 2011; Nicholl et al., 2013; de Lima, de Paulo and Higarashi, 2015), ramps for access into and out of the home (Carnevale et al., 2006; Nicholl et al., 2013) and additional electrical plug sockets (Nicholl et al., 2013).

Adaptations to the home can be expensive (Bourke-Taylor, Cotter and Stephan, 2014). Parents may be asked to pay for or contribute to these adaptations, but may not have the means to do so, leading to feelings of guilt (de Lima et al., 2015; Nicholl et al., 2013). Studies conducted in Norway, England, and Canada (countries with state-funded health care) and the USA reported that parents can feel like they have to fight to prove to professionals that the adaptations, technology, and support services required by their children should be publicly funded (Kirk and Glendinning, 2002; Dybwik et al., 2011; Woodgate et al., 2015; Currie and Szabo, 2019; Boss et al., 2020). Professionals also have to fight to justify the children's immediate and future need when they make applications for funding (Bourke-Taylor, Cotter and Stephan, 2014).

The purchasing, acquisition, and provision of the adaptations, technology, equipment and adequate supplies that enable the family to provide care at home can be stressful for both parents and professionals (Diehl, Moffitt and Wade, 1991; Kirk, 1999a; Kirk and Glendinning, 2002). In England, funding difficulties can arise because of disputes between primary, secondary and tertiary providers of care (Kirk and Glendinning, 2004), or between health and social services (Kirk, 1999a), who are each reported to believe that the other provider should pay or contribute. The cost of

adaptations may be one reason why some children and families do not have the adaptations that they require. Bourke-Taylor et al. (2014) report that 21% of homes where children aged 7 to 13 years with complex health care needs live do not have enlarged rooms, and 16% of homes do not have adapted toilet or hoists that are required. Not having the space or adaptations that are required is likely to cause challenges for caring for children with complex health care needs at home.

Although the home needs to be able to accommodate a child, their technology, equipment, medications and all the consumables required, this can be difficult (Heaton et al., 2005; Lindahl and Lindblad, 2011). The negative impact of children's medical technology upon the space in the homes of families of technology-dependent children who live in the UK, Ireland, Italy, Sweden, the USA, Canada, and Brazil was reported by eleven studies (O'Brien, 2001; Kirk and Glendinning, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Nicholl et al., 2013; Paddeu et al., 2015; de Lima, de Paulo and Higarashi, 2015; Carter et al., 2018; Wilkinson, Bray, et al., 2020).

The need for medical technology for children with complex health care needs uses up available space within the home (Kirk et al., 2005) and storage of equipment, such as specialist wheelchairs, and consumables within the home can also impinge on space in the home (O'Brien, 2001; Heaton et al., 2005; Lindahl and Lindblad, 2011; Nicholl et al., 2013). The need for carers or professionals to support the children's care at home and their round-the-clock presence within the home also consumes space in the home (Kirk and Glendinning, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Kirk, Glendinning and Callery, 2005; Samwell, 2012).

Studies from the UK, Sweden, Brazil and Italy found that the medical technology, equipment, consumables and carers can result in the home starting to feel more like a hospital (Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011; Samwell, 2012; de Lima, de Paulo and Higarashi, 2015; Paddeu et al., 2015; Carter et al., 2018; Lindahl and Kirk, 2018; Wilkinson, Bray, et al., 2020). Restructuring the home and changes to the home can make it look like a hospital and can cause stress and anxiety for parents and their children (Samwell, 2012; Nicholl et al., 2013; de Lima, de Paulo and Higarashi, 2015). The difficulties that families have in positioning (de Lima et al., 2015), storing (O'Brien, 2001; Heaton et al., 2005; Lindahl and Lindblad, 2011), or hiding or camouflaging (Carnevale et al., 2006) the technology, equipment and consumables by covering it up, or hiding it under furniture or in cupboards, so that it is not the first thing to be seen by the family and visitors to the home (Levine, 2005; Carnevale et al., 2006; Woodgate et al., 2015; Toly et al., 2017), compounds the feeling that the home is being overtaken. The families of technology-dependent children who require visible or audible technology are viewed by Levine (2005) to be at a disadvantage, as it is impossible to hide technology such

as lifts, ramps or wheelchairs. Limits to positioning electrical equipment can result from the technology needing to be situated near plug sockets (Heaton et al., 2005). Although it was evident that all of these factors can alter the meaning of home for the family members (Kirk, Glendinning and Callery, 2005), the literature paid little attention to how the sense and meaning of home was altered for children with complex health care needs and their family members.

The evidence about the impact of medical technology upon the home and use of spaces within the home came from ten 4-star articles (based on empirical studies) (Kirk and Glendinning, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Earle et al., 2006; Dybwik et al., 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Woodgate et al., 2015; Carter et al., 2018), eight 3-star articles (Diehl, Moffitt and Wade, 1991; Kirk, 1999a; O'Brien, 2001; Heaton et al., 2005; de Lima, de Paulo and Higarashi, 2015; Currie and Szabo, 2019; Boss et al., 2020; Wilkinson, Carter, et al., 2020), two 2-star articles (Paddeu et al., 2015; Kirk and Glendinning, 2002) and two 1-star articles (Levine, 2005; Samwell, 2012). Poor quality evidence (1-star and 2-star) was only used if supporting the findings of 4-star or 3-star articles. Consequently, the evidence presented in the above section is trustworthy.

2.5.3 The Impact of Living with Technology on Technology-Dependent Children

The impact of medical technology on life at home for the children is explored in this section.

All technology-dependent children are unique and have a varying range of need, cognition, communication and mobility. Some children may require 24-hour nursing or technological care, whilst others may require these types of care only part of the time. Although the literature reported both the positive and negative overlapping physical, emotional and psychological and social impacts of living with technology for children, far more negative impacts of technology on the children were reported than positive.

2.5.3.1 Physical impacts of living with technology for children

The positive impact of living with technology for children was that it is reported to enhance their health and wellbeing, function (González et al., 2017) and quality of life (Kirk, 2001; Earle et al., 2006; Nishigaki et al., 2016), by not only saving and/or supporting their life, but also making them feel healthier and more able to participate in typical childhood activities (Heaton et al., 2005; Levine, 2005; Carnevale et al., 2006; Earle et al., 2006; Lindahl and Lindblad, 2011). However, technology-dependent children often have mobility impairments (Hobson and Noyes, 2011) and require mobility devices such as wheelchairs (Carnevale et al., 2006; Nicholl et al., 2013). As such, a negative impact of living with technology for children is that unless they have the physical and cognitive ability to use an electric wheelchair, they are then reliant upon the technology, their parents (Levine, 2005) and

often nurses or carers to mobilise them (Carnevale et al., 2006), as well as to care for them (Hobson and Noyes, 2011; Samwell, 2012).

2.5.3.2 Psychological and emotional impacts of living with technology for children

Some children require constant supervision because of their health care needs and this can affect their feelings of freedom and privacy (Earle et al., 2006; Lindahl and Lindblad, 2011). Privacy and dignity issues can also arise from their personal care requirements and other procedures such as catheterisation (Hobson and Noyes, 2011). Another negative emotional and psychological impact for children is that they can worry about their life revolving around their technological and medical needs and the burden that this places upon their parent(s) (Earle et al., 2006; Lindahl and Lindblad, 2011).

The children's high level medical and physical needs can result in their emotional needs being overlooked (Diehl, Moffitt and Wade, 1991). Furthermore, if technology-dependent children have cognitive or communication difficulties, this can have a negative impact upon how they are integrated into family life (Wilson, Morse and Penrod, 1998). Cognitive or communication difficulties can result in some technology-dependent children being perceived to lack capacity and capability (by some family members and other people), which results in them not being given information, not being asked their opinion and not being involved in decision making (Wilson, Morse and Penrod, 1998; Carnevale et al., 2006; Earle et al., 2006). This can make some children feel isolated and disempowered (Wilson, Morse and Penrod, 1998; Carnevale et al., 2006; Earle et al., 2006). This, in turn, can manifest psychologically as depression, low self-esteem and/ or self-identity issues (Rehm and Bradley, 2005a), or behaviourally, as frustration and anger (Carnevale et al., 2006; Earle et al., 2006; Lindahl and Lindblad, 2011).

2.5.3.3 Social impacts of living with technology for children

Some technology-dependent children have reported that they want to engage in social activities and relationships and fit in with others from the world beyond the home (Rehm and Bradley, 2005a; Earle et al., 2006; Lindahl and Lindblad, 2011) and some require hearing, vision and communication equipment to be able to engage with others (Nicholl et al., 2013). Having friends is one of the things that makes most children happy (Earle et al., 2006), including technology-dependent children and their siblings (Levine, 2005). Although some children are reported to focus upon their friendships and interests more than their technology and equipment (Carnevale et al., 2006), technology which is visibly obvious can make them feel different to their peers (Rehm and Bradley, 2005a; Earle et al., 2006; Lindahl and Lindblad, 2011). As a result, some technology-dependent children are hypervigilant of other people's reaction to their differences (Lindahl and Lindblad, 2011).

Although Lindahl and Lindblad (2011) propose that the physical needs of technology-dependent children are best maintained within the home, and their minds are more stimulated outside of the home, Woodgate et al. (2015) note that the social needs of technology-dependent children often have to come second to their physical and health needs. Technology-dependent children are more likely to experience social isolation than their peers (Kirk, 1999a; Heaton et al., 2005; Earle et al., 2006; Lindahl and Lindblad, 2011; Nishigaki et al., 2016; Lindahl and Kirk, 2018) and this is a negative impact of living with technology for children. Reliance on technology and carers can limit children's opportunities, their feelings of freedom and their engagement in typical childhood experiences, such as sleep-overs at their friend's houses, because of being more confined to the home (Rehm and Bradley, 2005a; Lindahl and Lindblad, 2011). However, despite being more likely to be confined to the home, Carnevale et al. (2006) found that technology-dependent children do not always want friends to visit or stay over at their own house because they want to keep their technology secret.

Technology failures such as wheelchair malfunctions can be very distressing for children who can then become even more dependent upon their parents to support their socialisation whilst it is fixed (Carnevale et al., 2006). The absence of the wheelchair may mean a child cannot go out causing the whole family to become housebound (Carnevale et al., 2006) and affecting their child's ability to make and maintain friendships (Earle et al., 2006).

In spite of these reported negative impacts of technology on feelings of independence and privacy, emotional wellbeing and social relationships, some technology-dependent children still have hope about their future and believe that a time will come when they do not need the technology anymore (Earle et al., 2006). However, the opposite is more likely to be true as the technology that was initially used temporarily to aid their survival can 'become a permanent feature of their care' (Nicholl et al., 2013: 230).

Three articles which were weighted as 1-star (Levine, 2005; Samwell, 2012; González et al., 2017) were used in the section on the physical impacts of living with technology for technology-dependent children. However, these 1-star articles were only used to support the evidence from five articles (based on empirical work) weighted as 4-star (Kirk, 2001; Carnevale et al., 2006; Earle et al., 2006; Hobson and Noyes, 2011; Nicholl et al., 2013) and one article weighted as 3-star (Heaton et al., 2005). Evidence was also drawn from the meta-synthesis article (Lindahl and Lindblad, 2011).

Only articles weighted as 4-star (Carnevale et al., 2006; Earle et al., 2006; Hobson and Noyes, 2011, Lindahl and Lindblad, 2011) or 3-star quality (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998) were used in the

psychological and emotional impacts of living with technology for technology-dependent children section.

The evidence about the social impacts of living with technology for technology-dependent children was drawn from four 4-star articles (Carnevale et al., 2006; Earle et al., 2006; Nicholl et al., 2013; Woodgate et al., 2015), four 3-star articles (Kirk, 1999a; Heaton et al., 2005; Rehm and Bradley, 2005a; Nishigaki et al., 2016), and the meta-synthesis article (Lindahl and Lindblad, 2011). Only one 1-star article (Levine, 2005) was used. As such, the evidence about the physical, psychological and emotional, and social impacts of living with technology for technology-dependent children is trustworthy.

2.5.4 The Impact of Living with Technology on Siblings

The impact of life at home with medical technology for siblings is explored in this section.

It is important to consider how living with a technology-dependent child impacts upon siblings. Toly et al.'s (2017: 392) work in the USA notes that 'approximately 75% of families who are caring for a technology-dependent child also care for a well-child'. The lives and childhoods of siblings who have a technology-dependent brother or sister are different to siblings living in families without a technology-dependent child (Heaton et al., 2005; Lindahl and Lindblad, 2011; Toly et al., 2017). Although it is difficult to separate whether the positive and negative impacts of living with technology for siblings arise because of having technology in the home, and/or because of their brother or sister having complex health care needs, the findings of this review suggest that the negative impacts for siblings are more to do with the latter. It is also difficult as so few siblings are represented in the literature. When siblings have taken part in studies, authors have reported that they were reluctant to share their thoughts with the researcher; possibly the fact that interviews were conducted in the presence of their parents might have influenced their responses (Carnevale et al., 2006; Lindahl and Lindblad, 2011). In one study, sibling perspectives were reported on by their mothers (Toly et al., 2017). This makes it difficult to gain an understanding of how medical technology impacts life at home for siblings.

Although the literature reported both positive and negative physical, emotional, psychological and social impacts of living with a technology-dependent brother or sister, far more negative impacts were reported than positive and the impacts can overlap across these three domains. The positive and negative physical, emotional and psychological and social impacts of living with technology for siblings are now presented.

2.5.4.1 Physical impacts of living with technology for siblings

The first negative physical impact for siblings of technology-dependent children is that they are reported as often having to undertake more household chores than other children the same age (Heaton et al., 2005; Lindahl and Lindblad, 2011; Woodgate et al., 2015; Toly et al., 2017). They may even provide health or technological care for their technology-dependent sibling (Lindahl and Lindblad, 2011; Toly et al., 2017) despite being neither developmentally prepared nor professionally trained to deliver this care (Heaton et al., 2005). Older siblings are reported to take their technology-dependent sibling for hospital, GP or therapy appointments (Heaton et al., 2005; Lindahl and Lindblad, 2011). The literature also highlights how sleep can be disrupted for siblings (Lindahl and Lindblad, 2011), especially when they share a room with their technology-dependent brother or sister (Toly et al., 2017), demonstrating another negative physical impact for siblings.

2.5.4.2 Psychological and emotional impacts of living with technology for siblings

The positive impacts of having a technology-dependent brother or sister include the siblings being reported as being more mature, empathic and caring and less self-centred than other children the same age (Toly et al., 2017). Their cooperation and social skills can be better than those of their same-aged peers who do not have a technology-dependent sibling (Toly et al., 2017). However, more negative psychological and emotional impacts are reported in the literature than positive. These negative impacts can arise because parents can find it difficult to give their other children as much care and attention as they need, due to the level of attention required by their technology-dependent child (Kirk and Glendinning, 2004; Carnevale et al., 2006; Lindahl and Lindblad, 2011; González et al., 2017; Wilkinson, Bray, et al., 2020). The lack of time and attention given to the sibling(s) can negatively affect the parent-child (sibling) relationship (Carnevale et al., 2006; Dybwik et al., 2011; Toly et al., 2017) and can affect family functioning because siblings want and need to spend time with their family (Woodgate et al., 2015). Siblings are reported by parents to feel second best to their technology-dependent brother or sister or not loved (Lindahl and Lindblad, 2011). This can affect sibling bonds, especially when their technology-dependent sibling is not able to play (Toly et al., 2017), or is non-verbal (Carnevale et al., 2006). Siblings report feeling mixed emotions about their technology-dependent brother and sister (Toly et al., 2017). They worry about and are protective of their sibling (Toly et al., 2017), but some can feel resentful of them (Carnevale et al., 2006; Paddeu et al., 2015; Toly et al., 2017), or not like them (de Lima, de Paulo and Higarashi, 2015). Some siblings described feeling embarrassed to be seen with their technology-dependent brother or sister outside the house (Diehl, Moffitt and Wade, 1991; de Lima, de Paulo and Higarashi, 2015).

Living with a technology-dependent child can cause psychological and behavioural issues for siblings (Heaton et al., 2005; Paddeu et al., 2015; Toly et al., 2017). These issues can arise from living in a stressful and unpredictable home environment, the limitations on their social and school life,

and disruption to their sleep. Siblings can become distressed by witnessing the care that their technology-dependent brother or sister requires (Carnevale et al., 2006; Woodgate et al., 2015). Other siblings are constantly vigilant (O'Brien, 2001) so as to alert their parents if their technology-dependent sibling requires their attention (Toly et al., 2017). However, proxy reporting by mothers in Toly et al.'s (2017) study reported few mental health problems or negative emotions such as inappropriate anger, irritability or impatience in their child's sibling(s).

2.5.4.3 Social impacts of living with technology for siblings

The negative social impacts for siblings living with a technology-dependent brother or sister were highlighted in the literature. Having a technology-dependent sibling can limit family activities and social activities for siblings (O'Brien, 2001; Carnevale et al., 2006; Toly et al., 2017), which can have a considerable impact upon siblings' social wellbeing (Toly et al., 2017). The changes to the home can affect how family life is ordered (Kirk, Glendinning and Callery, 2005). The home can lack personal space for sibling(s) (Lindahl and Lindblad, 2011). Although the findings of this review suggest that the negative impacts of living with technology for siblings arise more because of their brother or sister's complex health care needs, some siblings reported not feeling able to invite friends round to their house (Diehl, Moffitt and Wade, 1991; Kirk, Glendinning and Callery, 2005) due to the high visibility of the technology or consumables (de Lima, de Paulo and Higarashi, 2015). The space in the home for the sibling(s) and their friends to play can be determined by the technology, equipment and consumables (Kirk, Glendinning and Callery, 2005) and/or the needs of their technology-dependent brother or sister or where they are located in the home (Woodgate et al., 2015).

Only 4-star and 3-star articles (based on empirical work) were used in the sections addressing the physical and social impacts of living with technology for siblings of technology-dependent children. One article weighted as 2-star (Paddeu et al., 2015) and two weighted as 1-star (González et al., 2017; Toly et al. 2017) were used in the section addressing psychological and emotional impacts of living with technology for siblings. These 1-star and 2-star articles supported the findings of five 4-star articles (Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Woodgate et al., 2015), five 3-star articles (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Heaton et al., 2005; de Lima, de Paulo and Higarashi, 2015; Wilkinson, Carter et al., 2020) and one meta-synthesis article (Lindahl and Lindblad, 2011). As such, the evidence about the physical, psychological and emotional and social impacts of living with technology for siblings is trustworthy.

2.5.5 The Impact of Living with Technology on Parents

The impact of medical technology upon life at home for parents who have a technology-dependent child is explored in this section and was the largest theme to emerge from the literature. This is not surprising since parents participated in 31 out of the 33 empirical studies.

Parents of technology-dependent children want to experience, and want their child/ren to experience, as normal and optimal a life as possible (Dybwik et al., 2011) and to meet all their child's needs at home and to give them a good life (Carnevale et al., 2006; Woodgate et al., 2015). The literature reported both positive and negative physical, emotional and psychological, social, and financial impacts on life at home for parents who have a technology-dependent child. Far more negative impacts of technology on parents were reported than positive. It is difficult to separate whether the positive and detrimental impacts of life at home with technology on parents are because of the technology in the home, and/or because of the complexity and unpredictability of their child's health care needs. Rather than being distinct, the four domains of physical, emotional, psychological, social and financial impacts often overlapped. Each of these four domains will now be presented.

2.5.5.1 Physical impacts of living with technology for parents

Only negative physical impacts for parents caring for their technology-dependent child were reported in the literature. Negative physical impacts include the physical demands placed on parents to provide technical, physical and/or personal care for their child (Nicholl et al., 2013; Woodgate et al., 2015; Boss et al., 2020; Wilkinson, Bray, et al., 2020). Parents are willing to put in this physical effort to enhance their child's quality of life despite the risks to their own physical health (Carnevale et al., 2006; González et al., 2017), such as back injuries or falls, as a result of lifting and carrying their child (Wilson, Morse and Penrod, 1998; Woodgate et al., 2015).

Sleep deprivation is a common issue for parents of technology-dependent children, contributing to physical and emotional exhaustion, depression, anxiety, parental ill health and relationship breakdown (Wilson, Morse and Penrod, 1998; Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011; Toly, Musil and Carl, 2012a; Woodgate et al., 2015; de Lima, de Paulo and Higarashi, 2015; Paddeu et al., 2015; Nishigaki et al., 2016; Carter et al., 2018; Currie and Szabo, 2019; Spratling and Lee, 2020). Sleep disturbance and deprivation can potentially affect parents' ability to provide safe, high quality care for their child (Paddeu et al., 2015; Spratling and Lee, 2020). There are several reasons why parental sleep deprivation can occur. The first is related to the psychological and emotional impact of having to remain vigilant about their child's health status 24 hours a day (O'Brien, 2001; Kirk and Glendinning, 2004; Heaton et al., 2005; Paddeu et al., 2015; Carter et al., 2018; Israelsson-Skogsberg et al., 2018; Currie and Szabo, 2019; Imperial-Perez and Heilemann, 2019), as there is no room for error whilst monitoring or attending to their child's technology or health status (Carnevale et al., 2006; Dybwik et al., 2011; Imperial-Perez and Heilemann, 2019). Parental sleep deprivation also occurs because of having to check on their child when an alarm sounds (Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Dybwik et al., 2011; Hobson and Noyes, 2011; Nishigaki et al., 2016; Spratling and Lee, 2020). Medical emergencies or life-threatening events can occur at any time of the day or night (González et al., 2017). Parents report having to go

to bed later than they would normally choose to because of waiting to give medication to their child or programming the technology at a certain time (Hobson and Noyes, 2011). Alternatively, parents often have to cover shifts when carers are not provided (Heaton et al., 2005) or when carers are perceived as being inexperienced or are considered to lack the necessary competences to deliver safe care for their child (Nishigaki et al., 2016; Nageswaran and Golden, 2017).

Another aspect to have a physical, psychological and emotional impact upon parents is that they can spend hours on the telephone (Wilson, Morse and Penrod, 1998) or online, battling for limited resources, accessing technical support from service providers (Heaton et al., 2005), or trying to find out information about their child's condition or technology (Diehl, Moffitt and Wade, 1991), as they often have to advocate for, organise or coordinate services for their child (Diehl, Moffitt and Wade, 1991; Heaton et al., 2005). The human aspect of fighting 'against the system' are reported by some parents as being more frightening than the technological aspects (Dybwik et al., 2011:4).

Families of technology-dependent children often experience a high turnover of staff who provide care for their child, resulting in another physical impact for parents – the extra time being spent in sharing information with new staff and training them to meet their child's needs (Dybwik et al., 2011).

An overlapping physical, emotional and psychological impact for parents is that parents can lack certainty about how their child's needs are going to be met in the future (O'Brien, 2001; Woodgate et al., 2015). Parents worry about how they will manage the physical aspects of their child's care as their child grows older, bigger and heavier, and as they grow older themselves, and are less physically capable of providing care for their child (Carnevale et al., 2006; González et al., 2017). Parents describe needing reassurance that they will not be solely responsible for their child's care when they become adults, as they worry that their child is not and will never be fully independent (Carnevale et al., 2006).

2.5.5.2 Psychological and emotional impacts of living with technology for parents

Although the literature reported both positive and negative psychological and emotional impacts of living with technology for parents who are caring for their technology-dependent child at home, far more negative impacts were identified than positive. These will be presented first.

Parents can grieve the loss of having a 'normal' child and 'normal' experience of parenthood (Kirk, Glendinning and Callery, 2005; Toly, Musil and Carl, 2012a; de Lima, de Paulo and Higarashi, 2015; Woodgate et al., 2015; Imperial-Perez and Heilemann, 2019) and this can disrupt their psychological and emotional health and

wellbeing (Lindahl and Lindblad, 2011; de Lima, de Paulo and Higarashi, 2015). Some parents adopt a 'normalising lens' whereby they view their child as 'typical' as a strategy to cope (Gardner, 2014).

Parents, typically mothers (Wilson, Morse and Penrod, 1998; Heaton et al., 2005; Black, Holditch-Davis and Miles, 2009; Toly, Musil and Carl, 2012a, 2012b; Gardner, 2014; González et al., 2017), are reported to require a high level of skills and competency to be able to meet (and often become an expert in) their child's ever-changing complex and intensive health care and technological needs (Kirk, 1999a, 2001; Kirk and Glendinning, 2002, 2004; Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011; Gardner, 2014; Woodgate et al., 2015; Carter et al., 2018; Boss et al., 2020). Taking responsibility for providing care at home can be daunting for parents who can be frightened about their ability to cope (Levine, 2005; Dybwik et al., 2011; Lindahl and Lindblad, 2011; Toly, Musil and Carl, 2012a; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Woodgate et al., 2015). Parents' ability to cope physically, psychologically and emotionally was a key theme identified in the literature.

Despite wanting their child to see them first as a parent (Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011), parents must provide health care in addition to the usual parental care (Black et al., 2009) (e.g. nurse or clinical caregiver, care manager, case manager, 'advocate', 'student', educator and 'detective') (Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Woodgate et al., 2015: 6; Currie and Szabo, 2019; Wilkinson et al., 2020). The many roles that parents have are rarely negotiated between professionals and parents (Kirk, 2001), despite being roles that parents are not properly qualified for and would not choose to undertake if their child's life did not depend upon it (Diehl et al., 1991; Carnevale et al., 2006; Woodgate et al., 2015; Kirk et al., 2005; Kirk, 2001; Dybwik et al., 2011; Kirk and Glendinning, 2002). Parents undertake an average of 'four different complex medical or nursing tasks a day' (Gardner, 2014: 818) and are often alone when undertaking these roles that can be difficult to manage and master (Nicholl et al., 2013; Nishigaki et al., 2016) and when making complex decisions with regard to their child's care. Through taking responsibility for these roles, parents - mostly mothers (Wilson, Morse and Penrod, 1998; Heaton et al., 2005; Hobson and Noyes, 2011; Toly, Musil and Carl, 2012a; González et al., 2017; Toly et al., 2017; Carter et al., 2018) - are often required to undertake procedures that cause their child pain or distress. Having to perform intensive and painful medical procedures that might include physical restraint (often over years or decades) can cause parents to become distressed and anxious (Imperial-Perez and Heilemann, 2019) and can define and redefine the parent-child relationship and affect parental identity (Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005). Hurting or distressing their child is outside of the role of parenting and can be in conflict with the parents' desire to protect and nurture their child (Wilson, Morse and Penrod, 1998; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Toly, Musil and Carl, 2012a; Woodgate et al., 2015; Toly et al., 2017; Currie and Szabo, 2019).

Several studies report that parents worry that their child's technology (O'Brien, 2001; Rehm and Bradley, 2005a; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Toly, Musil and Carl, 2012a; Nishigaki et al., 2016) or electricity (that their child's life depends upon) might fail (Sakashita, Matthews and Yamamoto, 2013). Parents feelings of safety are impacted by worrying constantly about the fragility of their child's life (Black, Holditch-Davis and Miles, 2009; Nicholl et al., 2013; Toly et al., 2017) and their child's premature death (Rehm and Bradley, 2005a; Carnevale et al., 2006; Imperial-Perez and Heilemann, 2019), not helped by living in a home in which the visible and audible technology acts as a permanent reminder (Nicholl et al., 2013; Toly et al., 2017). Predictions about how long their child will live is a source of uncertainty and, thus, stress and anxiety (O'Brien, 2001), yet parents report often not having anyone to talk to about their child's limited life expectancy (Diehl, Moffitt and Wade, 1991). These worries about the fragility of their child's life contribute to sleep deprivation, thereby having both a physical and a psychological and emotional impact upon parental health and wellbeing.

More than a third of studies included in the review reported that it can be stressful for parents to balance their children's fragile life and care needs with family life (Wilson, Morse and Penrod, 1998; O'Brien, 2001; Kirk, Glendinning and Callery, 2005; Earle et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; Woodgate et al., 2015; Nishigaki et al., 2016; Toly et al., 2017; Boss et al., 2020). As reported by Boss et al. (2020: 178), 'family life is inextricable' from the schedules of care that their child requires. The routines of care and the demands of technology at home (Kirk and Glendinning, 2004) are governed by the clock (Dybwik et al., 2011; Carter et al., 2018) and become a significant part of daily life for the children and their families (Nicholl et al., 2013; Boss et al., 2020). Although parents can identify the ways in which their family life is like that of 'typical' families (Rehm and Bradley, 2005a: 813), they come to accept that they are not 'normal' families and create their own normality (Lindahl and Lindblad, 2011: 250). One way of creating a new 'normal' is by striving to create routines that mirror those of typical families (Levine, 2005; Rehm and Bradley, 2005a; Carnevale et al., 2006; Hobson and Noyes, 2011; Samwell, 2012; Toly, Musil and Carl, 2012a; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015). Eight studies reported that parents felt more stable and more able to cope with their child's challenging and overwhelming technological and care needs by adapting their lifestyle and initiating a routine to organise their time effectively (O'Brien, 2001; Kirk and Glendinning, 2004; Rehm and Bradley, 2005a; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011; Toly, Musil and Carl, 2012a; Gardner, 2014; Woodgate et al., 2015; Toly et al., 2017, 2019). However, these routines can change as the children grow (Heaton et al., 2005) and the number, type and size of equipment increases (Nicholl et al., 2013). Life can become unstable, uncertain, unpredictable and chaotic (Carnevale et al., 2006; Toly, Musil and Carl, 2012a) after the children have experienced an illness exacerbation or when there are changes to their health status (Heaton et al., 2005; Toly, Musil and Carl, 2012a). Multiple, frequent and unexpected changes to family life are common experiences for parents who have a technology-dependent child (O'Brien, 2001; Toly et al., 2012a). It can be difficult for parents to create routines and have the 'normal' life that they strive for when

their child has unpredictable complex health care needs, and this has implications for parental mental health (Heaton et al., 2005; Rehm and Bradley, 2005a; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Toly, Musil and Carl, 2012a; de Lima, de Paulo and Higarashi, 2015).

Family life and parenting are usually private activities (unless a child is being harmed or is at risk of harm), but a major theme across almost half of the literature included in this review was the lack of privacy that families with technology-dependent children had in their home (Wilson, Morse and Penrod, 1998; Kirk and Glendinning, 2002, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Rehm and Bradley, 2005a; Kirk, Glendinning and Callery, 2005; Dybwik et al., 2011; Lindahl and Lindblad, 2011; Samwell, 2012; Toly, Musil and Carl, 2012a; Nicholl et al., 2013; Woodgate et al., 2015; Paddeu et al., 2015; Currie and Szabo, 2019; Boss et al., 2020). This lack of privacy, which can negatively impact upon parental psychological and emotional wellbeing and family functioning, was caused by the constant presence of professionals and carers who visit or support the care of their child with complex health care needs, both day and night. Parents can feel uncomfortable about their family and social interactions and discussions taking place in front of professionals and carers (Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011; Samwell, 2012). For example, they do not feel as able to control their child's/children's behaviour as a result of being under this watchful gaze (Lindahl and Lindblad, 2011) if they feel they may be judged. Parents cannot even retreat to the privacy of their bedroom as nurses or carers may come to wake them up or request their assistance if their child needs medical attention (Wilson, Morse and Penrod, 1998; Rehm and Bradley, 2005a).

However, although caring for their technology-dependent child at home can be a considerable burden for parents (Dybwik et al., 2011; González et al., 2017; Kirk and Glendinning, 2002; O'Brien, 2001), providing home-based care for their technology-dependent child can also have some positive impacts upon their psychological and emotional health and wellbeing. Parents report feeling more in control of their child's care at home (Kirk and Glendinning, 2004; Lehoux, Saint-Arnaud and Richard, 2004) than when their child is being cared for in hospital (Kirk, 2001) and this supports their ability to cope. Parents gain knowledge and skills that they require to meet their child's needs through experiential and intuitive learning and training when they are at home (Spratling and Lee, 2020; Woodgate et al., 2015; de Lima et al., 2015; Gardner, 2014; Dybwik et al., 2011; Kirk and Glendinning, 2002; Kirk et al., 2005). Parents were reported to initially follow the training and guidance provided by medical professionals down to the letter but over time become less likely to follow the 'rules' and consult with professionals less as they integrate the technology into their daily routine (Kirk and Glendinning, 2002; Black, Holditch-Davis and Miles, 2009; Gardner, 2014; Nishigaki et al., 2016; Spratling and Lee, 2020). It can take more than six months for parents to get used to new technology (Kirk and Glendinning, 2004). However, for the most part, parents do become more comfortable, confident and competent with the technology and become experts in providing high quality care for their child

and this helps them to cope (Wilson, Morse and Penrod, 1998; O'Brien, 2001; Kirk, 2001; Kirk and Glendinning, 2002, 2004; Earle et al., 2006; Black, Holditch-Davis and Miles, 2009; Dybwik et al., 2011; Lindahl and Lindblad, 2011; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Nishigaki et al., 2016).

Parents report that they find caring for their technology-dependent child to be a rewarding task (Carnevale et al., 2006; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011). This has a positive psychological and emotional impact for parents. Despite their life being governed by the clock and the procedures that their child requires to remain healthy, parents still report having a happy life (Dybwik et al., 2011). Parents can also become experts at focusing upon the positive aspects and values of life, which helps them to cope and to remain resilient (Wilson, Morse and Penrod, 1998; O'Brien, 2001; Dybwik et al., 2011; Lindahl and Lindblad, 2011; Woodgate et al., 2015; Nishigaki et al., 2016; Toly et al., 2019; Toly, Blanchette and Musil, 2019).

2.5.5.3 Social impacts of living with technology for parents

Having a child who relies upon medical technology can have a positive psychological and emotional impact upon parents by making some marital/couple relationships stronger (O'Brien, 2001; Heaton et al., 2005; Hobson and Noyes, 2011), especially when each partner shares the responsibility for providing care to their child (Woodgate et al., 2015). However, one fifth of the studies included in the review reported that parents of technology-dependent children are far more likely to experience problems and conflict and to separate or divorce than the general population (O'Brien, 2001; Kirk and Glendinning, 2002; Carnevale et al., 2006; Paddeu et al., 2015; González et al., 2017). The biggest contributing factors to relationship breakdown are the tiredness and exhaustion experienced by the parents (Carnevale et al., 2006; Woodgate et al., 2015) and the lack of time that parents have to attend to their own health and social care needs (O'Brien, 2001), their couple relationship (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998; O'Brien, 2001; Heaton et al., 2005; Dybwik et al., 2011; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011; Nicholl et al., 2013; Gardner, 2014; Woodgate et al., 2015) and family relationships (Dybwik et al., 2011; Toly et al., 2017).

More than half the papers included in the review reported that caring for a technology-dependent child at home can have a detrimental impact for the parents' social relationships (O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Levine, 2005; Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; Paddeu et al., 2015; Woodgate et al., 2015; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017, 2019; González et al., 2017; Carter et al., 2018; Lindahl and Kirk, 2018; Toly, Blanchette and Musil, 2019). Parents find it almost impossible to plan any activities for themselves or other family members: the unpredictability of their child's condition and the speed that their health status can deteriorate means that parents must be available at all times (O'Brien, 2001; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011). Maintaining connections with extended family or friends is difficult when their child's care needs are so

time-consuming, unpredictable, complex and life threatening (O'Brien, 2001; Dybwik et al., 2011; González et al., 2017). Engaging in hobbies, leisure activities (Rehm and Bradley, 2005a; Hobson and Noyes, 2011), or holidays is also difficult for the same reason and/or because parents do not have any safe and accessible means to transport their child and their heavy and unwieldly technology and equipment (Kirk and Glendinning, 2004). The frequent disruptions to the family's routine (O'Brien, 2001) and the extra time to provide their child's care often coincides with social schedules, such as the start of the school day (Heaton et al., 2005; Nishigaki et al., 2016; Nageswaran and Golden, 2017; Israelsson-Skogsberg et al., 2018).

Parents cannot be spontaneous because leaving the home with their child and the technology that they require, even for short periods of time, to carry out typical routines such as grocery shopping, takes great organisation and effort (Diehl, Moffitt and Wade, 1991; Rehm and Bradley, 2005a; Hobson and Noyes, 2011). Having left the home with their child, they might have to return home again earlier than expected, because of their child's unpredictable health care needs, and/or their need for medical technology (Heaton et al., 2005), medication, feeding and therapy (Diehl, Moffitt and Wade, 1991; Kirk and Glendinning, 2004). The reactions and attitudes by members of the public, such as being stared at, especially when parents are performing procedures such as suctioning their child can make parents feel upset and that it is not worth the effort to go out (Diehl, Moffitt and Wade, 1991; Carnevale et al., 2006; Lindahl and Lindblad, 2011). Parents can encounter people who perceive that their child's life has no value (Carnevale et al., 2006). These factors can lead to self-imposed as well as socially created isolation (Levine, 2005).

Parents can become housebound, socially isolated and lonely, and the home can come to feel like a prison because of not being able to maintain their social connections and the reactions and attitudes of people in the community (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Levine, 2005; Heaton et al., 2005; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; de Lima, de Paulo and Higarashi, 2015; Paddeu et al., 2015; Woodgate et al., 2015; Toly et al., 2017, 2019; González et al., 2017).

2.5.5.4 Financial impacts of living with technology for parents

More than half of the studies reported the financial implications for parents of caring for their technology-dependent child at home (Kirk, 1999a; O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Rehm and Bradley, 2005a; Heaton et al., 2005; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Hobson and Noyes, 2011; Samwell, 2012; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Gardner, 2014; Paddeu et al., 2015; Woodgate et al., 2015; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017, 2019; González et al., 2017; Lindahl and Kirk, 2018; Boss et al., 2020; Wilkinson, Bray, et al., 2020). Technology-dependent children often require extensive technology, equipment, medication and therapies, modifications to the home and a specialist vehicle for transport (Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Toly et al., 2019).

Parents often still have to contribute or pay for these even when they live in a country whose Government provides state funding for a child's serious health care needs (O'Brien, 2001). Families can experience increased household expenditure because of the additional laundry, heating and electricity costs required by their child. Families may have extra transport costs to take their child to hospital or therapy appointments (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Kirk and Glendinning, 2004; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; González et al., 2017) or for play and leisure activities (Bourke-Taylor, Cotter and Stephan, 2014). Families may also incur additional costs through providing refreshments for carers (Samwell, 2012).

Having to leave paid work, modify rooms or extend the home can lead to a reduction in household income and the need to rely upon state benefits (Diehl, Moffitt and Wade, 1991; Kirk and Glendinning, 2004; Rehm and Bradley, 2005a; Heaton et al., 2005; Levine, 2005; Carnevale et al., 2006; Hobson and Noyes, 2011; Lindahl and Lindblad, 2011; Samwell, 2012; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; de Lima, de Paulo and Higarashi, 2015; González et al., 2017; Toly et al., 2019). Two studies conducted in Canada (Carnevale et al., 2006; Woodgate et al., 2015) and one in Spain (González et al., 2017) suggested that the funding available to help offset the loss of earnings and increased household expenditure (Carnevale et al., 2006) is insufficient (Woodgate et al., 2015; González et al., 2017). Often parents do not know what help is available or how to access it (Diehl, Moffitt and Wade, 1991). Ten studies reported that the fear and insecurity created through worrying about money can cause parents immense stress and strain and they can feel a loss of control over their lives which, in turn, can affect family functioning and psychological wellbeing (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998; O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Carnevale et al., 2006; Nicholl et al., 2013; de Lima, de Paulo and Higarashi, 2015; Paddeu et al., 2015; Toly et al., 2017; González et al., 2017; Imperial-Perez and Heilemann, 2019).

Although one article weighted as 2-star (Paddeu et al., 2015) and one weighted as 1-star (González et al., 2017) were drawn upon to provide empirical evidence of the physical impacts of living with technology for parents, these 1-star and 2-star articles were used in conjunction with eleven 4-star articles (Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Toly, Musil and Carl, 2012b; Nicholl et al., 2013; Woodgate et al., 2015; Carter et al., 2018; Israelsson-Skogsberg et al., 2018; Imperial-Perez and Heilemann, 2019) and twelve 3-star articles (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998; Kirk, 1999a; O'Brien, 2001; Heaton et al., 2005; de Lima, de Paulo and Higarashi, 2015; Nishigaki et al., 2016; Nageswaran and Golden, 2017; Currie and Szabo, 2019; Boss et al., 2020; Wilkinson, Carter, et al., 2020; Spratling and Lee, 2020).

Most evidence about the psychological and emotional impacts of living with technology for parents came from 4-star articles (Kirk, 2001; Kirk and Glendinning, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Toly, Musil and Carl, 2012a, 2012b; Nicholl et al., 2013; Woodgate et al., 2015; Carter et al., 2018; Imperial-Perez and Heilemann, 2019) and the meta-synthesis article (Lindahl and Lindblad, 2011). When evidence from a 2-star article (Paddeu et al.,

2015) or 1-star articles (Levine, 2005; Samwell, 2012; González et al., 2017; Toly et al. 2017) was included, these were only used to support the 4-star and 3-star evidence about the psychological and emotional impacts of living with technology for parents.

Similarly, in the section on the social impacts for parents of living with technology, two 2-star articles (Paddeu et al., 2015; Kirk and Glendinning, 2002) and two 1-star articles (Levine, 2005; González et al., 2017) were only used to support the findings of nine 4-star articles (Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; Woodgate et al., 2015; Carter et al., 2018; Israelsson-Skogsberg et al., 2018) and nine 3-star articles (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998; O'Brien, 2001; Heaton et al., 2005; Rehm and Bradley, 2005a; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Nishigaki et al., 2016; Nageswaran and Golden, 2017), adding to the trustworthiness of the evidence.

Likewise, in the section addressing the financial impact on parents of living with technology, two 2-star articles (Paddeu et al., 2015; Kirk and Glendinning, 2002) and three 1-star articles (Levine, 2005; Samwell, 2012; González et al., 2017) were used to support the evidence from eight 4-star articles (Kirk and Glendinning, 2004; Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Woodgate et al., 2015; Imperial-Perez and Heilemann, 2019) and ten 3-star articles (Diehl, Moffitt and Wade, 1991; Kirk, 1999a; O'Brien, 2001; Heaton et al., 2005; Rehm and Bradley, 2005a; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2019; Boss et al., 2020; Wilkinson, Carter, et al., 2020). Evidence was also drawn from the meta-synthesis article (Lindahl and Lindblad, 2011). As such, the evidence about the physical, psychological and emotional, social and financial impacts of living with technology for parents is trustworthy.

2.5.6 The Impact of Living with Technology on Relationships with Extended Family Members

Four studies reported that parents of technology-dependent children who have supportive extended family members, especially single parents (Woodgate et al., 2015), coped with caring for their child because of this support (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Black, Holditch-Davis and Miles, 2009). Female relatives are the most likely to provide practical and material support (Black, Holditch-Davis and Miles, 2009). Whilst mothers of technology-dependent children are reported as being the most likely to receive emotional support from extended family members, fathers are expected to be strong and to cope, even though they can be their child's main caregiver and equally in need of support as mothers (Hobson and Noyes, 2011).

Even though parents of technology-dependent children have a great need for practical, material and emotional support, not all families have supportive extended families (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Kirk and Glendinning, 2002; Carnevale et al., 2006; Hobson and Noyes, 2011; Paddeu et al.,

2015; González et al., 2017). Having a child whose needs are so complex may mean that extended family members fear taking responsibility for the child's care (Diehl, Moffitt and Wade, 1991; Hobson and Noyes, 2011). Older relatives such as grandparents may not have the physical ability to provide care for their grandchild and their technology or equipment (O'Brien, 2001). It can be difficult for parents to maintain connections with their family and friends due to the demands of caring for their child (O'Brien, 2001). Alternatively, geographical separation (Hobson and Noyes, 2011) and divorce (Carnevale et al., 2006; O'Brien, 2001; González et al., 2017; Kirk and Glendinning, 2002; Paddeu et al., 2015) can result in reduced access to the extended family. Some extended family members have been reported as telling parents to have their child institutionalised (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Carnevale et al., 2006). Lack of support from extended family members may result from feelings of guilt when the child's condition is genetic (Diehl, Moffitt and Wade, 1991).

Although evidence from two 2-star articles (Paddeu et al., 2015; Kirk and Glendinning, 2002) and one 1-star article (González et al., 2017) has been drawn upon in the above section, the quality of the evidence about the impact of living with technology on relationships with extended family members is trustworthy as these articles have only been used to support the evidence of 4-star (Carnevale et al., 2006; Hobson and Noyes, 2011; Woodgate et al., 2015) and 3-star articles (Diehl, Moffitt and Wade, 1991; Kirk, 1999a; O'Brien, 2001; Heaton et al., 2005; Black, Holditch-Davis and Miles, 2009).

Formal respite becomes very important for parents with little or no family support (Heaton et al., 2005; Kirk, 1999a; Kirk and Glendinning, 2002). The need for, and availability of, respite will now be discussed.

2.6 Theme Three: Respite Needs

Technology-dependent children have complex and intensive care needs. More than half of the studies discussed the need for parents to have access to support and respite[11] opportunities, that can be 'inside and outside the home' (Dybwik et al., 2011: 6). Respite can help parents avoid becoming physically and emotionally burnt-out and, thus, providing less effective or safe care for their child (Wilson, Morse and Penrod, 1998; Kirk, 1999a; O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Kirk, Glendinning and Callery, 2005; Levine, 2005; Heaton et al., 2005; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Paddeu et al., 2015; Woodgate et al., 2015; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017; González et al., 2017; Toly, Blanchette and Musil, 2019; Imperial-Perez and Heilemann, 2019; Boss et al., 2020; Spratling and Lee, 2020).

[11] Respite or short breaks are when a child with complex health care needs is cared for by individuals outside of the family for a short period of time to provide the family with a break from intensive caring to promote their health and wellbeing.

As discussed in the last section, many parents lack physical and emotional support from friends, as well as from their extended family, meaning that formal respite is the only option (Diehl, Moffitt and Wade, 1991; O'Brien, 2001; Kirk and Glendinning, 2002; Carnevale et al., 2006; Hobson and Noyes, 2011; Paddeu et al., 2015; González et al., 2017; Toly, Blanchette and Musil, 2019). Obtaining safe formal respite is challenging for families (Kirk and Glendinning, 2004) and some families do not have access to this (Heaton et al., 2005; Kirk, 1999a; Kirk and Glendinning, 2002) and may become extremely isolated (Carnevale et al., 2006). Local health and social care services are usually inappropriate for technology-dependent children, and unable to provide the level or type of care that they require (Kirk and Glendinning, 2004; de Lima, de Paulo and Higarashi, 2015). Even though many health care professionals are involved in a child's care (Kirk and Glendinning, 2002, 2004; Heaton et al., 2005; Dybwik et al., 2011; Samwell, 2012), they may lack the necessary competence and confidence to meet the child's care needs (Kirk and Glendinning, 2002; Dybwik et al., 2011; Kirk, 1999a). It takes a lot of time and energy to recruit and train carers to be able to meet their child's specialist care needs (Kirk, 1999a, 2001). Trusting carers to look after their child is difficult for parents (Wilson, Morse and Penrod, 1998; Heaton et al., 2005; Gardner, 2014; Woodgate et al., 2015; Castor et al., 2018; Lindahl and Kirk, 2018). Parents cannot leave their child alone with carers, especially overnight (Kirk, 1999a), until they know that carers (paid and/or unpaid) and professionals have the necessary skills, competence, and confidence to meet their child's medical and technological care needs (Nageswaran and Golden, 2017; Kirk and Glendinning, 2004; Kirk, 1999a, Kirk and Glendinning, 2002; Diehl et al., 1991; Kirk, 2001; Kirk et al., 2005; O'Brien, 2001). The amount and type of support that families can receive is often geographically dependent and not always related to the child's level of need (Kirk and Glendinning, 2004; Kirk, 1999a; Lindahl and Lindblad, 2011; Nageswaran and Golden, 2017; Heaton et al., 2005).

Parents generally prefer home-based respite, as this means that their child remains in a familiar environment and can avoid the risk of cross infection (Lehoux, Saint-Arnaud and Richard, 2004; de Lima, de Paulo and Higarashi, 2015; Boss et al., 2020). Furthermore, bulky equipment does not have to be transported (Bourke-Taylor, Cotter and Stephan, 2014; Toly et al., 2019; Wilkinson, Bray, et al., 2020). However, hospital or children's hospice based respite is often the only feasible option (Kirk and Glendinning, 2004).

Respite is essential for enabling parents to safely continue providing the round the clock specialised medical and technological care that their child requires to remain at home with their family (Wilson, Morse and Penrod, 1998; Kirk, 1999a; O'Brien, 2001; Kirk and Glendinning, 2002, 2004; Kirk, Glendinning and Callery, 2005; Levine, 2005; Heaton et al., 2005; Carnevale et al., 2006; Lindahl and Lindblad, 2011; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; Bourke-Taylor, Cotter and Stephan, 2014; Paddeu et al., 2015; Woodgate et al., 2015; de Lima, de Paulo and Higarashi, 2015; Toly et al., 2017; González et al., 2017; Toly, Blanchette and Musil, 2019; Imperial-Perez and Heilemann, 2019; Boss et al., 2020; Spratling and Lee, 2020).

Although evidence from two 2-star articles (Paddeu et al., 2015; Kirk and Glendinning, 2002) and three 1-star articles (Levine, 2005; Samwell, 2012; González et al., 2017) have been used in the above section on respite needs, these articles have only been used to support the findings of twelve 4-star articles (Kirk, 2001; Kirk and Glendinning, 2004; Lehoux, Saint-Arnaud and Richard, 2004; Kirk, Glendinning and Callery, 2005; Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011; Nicholl et al., 2013; BourkeTaylor, Cotter and Stephan, 2014; Woodgate et al., 2015; Castor et al., 2018; Imperial-Perez and Heilemann, 2019) and eleven 3-star articles (Diehl, Moffitt and Wade, 1991; Wilson, Morse and Penrod, 1998; Kirk, 1999a; O'Brien, 2001; Heaton et al., 2005; Gardner, 2014; de Lima, de Paulo and Higarashi, 2015; Nageswaran and Golden, 2017; Boss et al., 2020; Wilkinson, Carter, et al., 2020; Spratling and Lee, 2020). Evidence was also drawn from the meta-synthesis article (Lindahl and Lindblad, 2011) and the systematic, integrative review (Lindahl and Kirk, 2018). This demonstrates that the evidence about respite needs is trustworthy.

2.7 Strengths and Limitations of the Review

Employing the integrative review method (Kirkevold, 1997; Cooper, 1998; Whittemore and Knafl, 2005) and using the MMAT (Pluye et al., 2011) has allowed a comprehensive search of the literature and a critical review and synthesis of 43 papers in an integrated and structured way. This is the only review to focus on how medical technology impacts upon the home and life at home for technology-dependent children and their immediate and wider family.

A strength of this review is that the methodological quality of the included articles based on empirical studies was appraised, therefore allowing weighting of the evidence and adding context to the trustworthiness of the conclusions drawn. Very few other integrative reviews of children with complex health care needs have done this. Rehm's (2013) review about parenting children with complex chronic conditions used MMAT but did not describe how it had been used or the methodological quality of the studies. Although the MMAT (Pluye et al., 2011) revealed that the quality of the papers included in this review is variable, the consistent findings across the 35 studies (43 papers) have enabled me to identify gaps in the knowledge and justify the need to undertake the study that is reported in this thesis.

This literature review provides a contemporary insight into the challenges that families who have technology-dependent children have faced since home-based care became the model of care in 1988. A strength of this review is that the impact of 13 major categories of technology and equipment (Table 2.4) on the home and different members of a family who live with the technology in the home, rather than health and social care professionals, are examined. The findings of this review of 41 papers (not including the meta-synthesis study and integrative review which include some of the 43 papers, to avoid double-reporting) are representative of

over 952 parents, 181 families, 79 technology-dependent children or young people, 46 siblings and two grandmothers (Appendix 7).

A limitation of the review is that most studies were small-scale studies, although there were three exceptions to this (Diehl, Moffitt and Wade, 1991; Toly, Musil and Carl, 2012a; Nicholl et al., 2013). Another limitation is that although the meta-synthesis and integrative review included doctoral theses, individual doctoral thesis were not included in the eligibility criteria for this review, thereby potentially missing the most contemporary knowledge.

2.8 Conclusion

The main aim of this integrative literature review was to answer the question of 'How does medical technology impact upon the home and life at home for technology-dependent children and their immediate and wider family?' The key literature is over a decade old and mostly highlights the negative impacts of caring for children and young people with complex health care needs at home, with less focus on how medical technology impacts the home and life at home.

Whilst some positive impacts of caring for their technology-dependent child at home were noted, the detrimental impacts on the physical, emotional and psychological health and wellbeing, social relationships, familial relationships and functioning were reported extensively. This was particularly evident for parents who also experienced detrimental impacts on their financial wellbeing. The need for respite to support the parents to continue to provide technology orientated, home-based care to their child is well-established.

Although core to the literature search, the impact of medical technology on the physical structure of the home and the sense and meaning of home was the aspect that had received the least research attention, indicating a gap in the literature that needs addressing.

It is noteworthy that the four empirical studies conducted in the UK do not necessarily reflect contemporary technology use because they are all somewhat dated, having collected data in or prior to 1999 (Kirk's five papers), 2005 (Heaton), 2011 (Hobson and Noyes) and 2012 (Samwell).

A gap in the knowledge about the impact of medical technology upon the home and life at home from the perspectives of technology-dependent children, siblings and grandparents is evident. Without a clearer perspective of the impact of technology on the home and family life for all members of a family, there is insufficient evidence to inform the future development and

provision of appropriate and effective resources and support that best meet the needs of the whole family.

This study will address these deficiencies. The research question and objectives will now be presented.

2.9 Research Question

How does medical technology impact upon the home and life at home for children, young people and adults (aged 5-25 years) with complex health care needs and their immediate and wider family members?

2.10 Research Objectives

The objectives of this study are to:

1. identify the technologies or equipment that are required for children with complex health care needs to live at home.
2. identify whether and how the home is changed by the presence of medical technology.
3. identify how different members of a family with a child who has complex health care needs experience life at home with medical technology.

Chapter 3: Methodology and Methods

3.1 Introduction

In this chapter, I will begin with a presentation of the methodology chosen and I will address the ontological and epistemological positioning that influenced and underpinned the data collection and analysis methods. I will then move onto the methods section and will provide the rationale for my choice of the qualitative data collection methods of auto-driven photo-elicitation interviews and semi-structured interviews. Following this, I will discuss sampling, and the recruitment and data generation procedures, and the rewards and challenges of these. I will then present the seven-stage thematic analysis method. Reflection, reflexivity and ethical considerations are woven throughout the chapter to evidence the trustworthiness of this study.

3.2 Methodology

In this section of the chapter I will present my ontological, epistemological and methodological positioning, situating myself as a researcher and providing some context for my choice of approach to the study.

3.2.1 Positioning my Research

I have always been passionate about promoting equality and equity for those who are disadvantaged through gathering a holistic understanding of their situation, supporting and empowering them to have better lives. This passion comes from my education, training and employment, as well as from personal experiences. In this study, my focus has been on developing knowledge about the impact of medical technology on the home and life at home for technology-dependent children and their family members.

Technology-dependent children and their families can experience multiple disadvantages and social isolation as a result of their child's complexity of need. The research gap about how medical technology impacts the home and life at home for technology-dependent children and their families drives me to help their voices to be heard. As such, the main foci for this study are the accounts of children and their family members, to explore the impact of medical technology for their home and lives. I knew from early on that my research fitted within a qualitative approach as I was invested in engaging and interacting with technology-dependent children and their family members in a holistic and empowering way. I wanted to ensure that whatever approach I took, my study participants would feel able to express their thoughts, feelings and needs. I wanted to make meaning and learn about how medical technology impacted upon their home and life at home from them.

3.2.2 Methodology

Methodology refers to the philosophical approaches that we have to 'discovering knowledge in a systematic way' (Killam, 2013: no pagination). A qualitative methodology was the most appropriate way to mutually construct a deep and detailed understanding (Silverman, 1993; Payne and Payne, 2004; McLaughlin, 2012) of how children and families observe, make sense of and describe their home and their lives with medical technology. I dismissed the use of a quantitative approach as it is objective and deductive and removes social context (McCoyd et al., 2009), and was therefore less compatible with my research question.

The big three (Kahlke, 2014) qualitative methodological approaches of Grounded Theory (Glaser and Strauss, 1967, 2017; Corbin and Strauss, 1990; Strauss and Corbin, 1998), phenomenology (Husserl, 1965, 1973; Gadamer, 1996), and ethnography (Malinowski, 1922) were carefully considered for this study. These approaches are compatible with my beliefs about how knowledge is constructed and my theoretical and philosophical framework. However, my research problem and question did not easily fit into any of these single established methodological approaches. I was not striving to develop a theory, so the selection of grounded theory was not appropriate (Caelli, Ray and Mill, 2003; Cooper and Endacott, 2007; Percy, Kostere and Kostere, 2015). Neither was I aiming to investigate the essences of the cognitive processes of lived experiences in depth (Caelli, Ray and Mill, 2003; Cooper and Endacott, 2007; Percy, Kostere and Kostere, 2015), so this meant phenomenology was not appropriate. The lives of technology dependent children and their family members are hectic, busy and unpredictable because of the children's around-the-clock complex health care needs. I did not wish my research to be a burden to the families, and consequently, did not want to be overtly or covertly observing or interacting with family members in their homes for extended periods of time to investigate a culture. This meant that the selection of ethnography was not appropriate (Caelli, Ray and Mill, 2003; Kahlke, 2014; Percy, Kostere and Kostere, 2015). Instead, a generic qualitative methodology (Percy, Kostere and Kostere, 2015) that 'draws on the strengths of … qualitative approaches' (Bellamy et al., 2016: 671) was selected for this study. I wanted to obtain a broad understanding of how medical technology impacts upon the home and life at home and my beliefs aligned to Percy, Kostere and Kostere's (2015) beliefs about consistency and authenticity. Percy, Kostere and Kostere (2015) propose that a generic qualitative approach is appropriate for research which seeks to gain an understanding of people's 'attitudes, opinions, or beliefs about a particular issue or experience'.

Generic qualitative researchers are typically criticised for their lack of ontological, epistemological and methodological clarity (Caelli, Ray and Mill, 2003; Atkinson and Delamont, 2006; Pasque et al., 2012; Kahlke, 2014). I did not want my ontological and

epistemological positioning to be an omission that might impact upon the perceived trustworthiness and authenticity of this study, so these will now be presented.

3.2.3 Ontology

Ontology is the nature of reality and assumptions or attitudes about what can be known about it (Lincoln and Guba, 1985). Ontology determines whether we think 'social and physical worlds are objective and exist independently of humans, or subjective and exist only through human action' (Orlikowski and Baroudi, 1991: 8). Having a relativist ontological position, which underpins the constructivist research paradigm (Denzin and Lincoln, 2005; Killam, 2013), I believe that there is no single reality or 'truth' to be known: 'reality does not exist outside the individual' (Killam, 2013: no pagination). I believe that reality is socially constructed, subjective (Orlikowski and Baroudi, 1991; Bryman, 2012; O'Gorman and MacIntosh, 2015), multiple (Guba, 1990; Sandelowski, 1993; Rolfe, 2006), ever changing (Guba, 1990), bound by context (Killam, 2013; Braun and Clarke, 2019) and relative to how the individual perceives or depicts it (Sandelowski, 1993; Rolfe, 2006; Edirisingha, 2012). It is dependent upon an individual's processes of 'reflection, exploration and iteration' (Hothersall, 2018: 3).

Having a relativist ontology means that I believe that people create reality through dialectical processes and social interaction. My professional (social worker) and personal value base means that I wanted to adopt a qualitative approach as this would both empower participants and allow me to actively engage and interact *with* them to mutually construct meaning. I wanted to avoid treating participants as a research resource (Silverman, 2006; Thompson, 2006). As recommended by Payne (2005), I wanted to ensure that participants could express their thoughts, feelings and needs during this study. I was interested in how children and their families remake their everyday situation (Bowling 2014), and how they construct and reconstruct their understandings (Bryman 2012) of having medical technology in their personal space. Using a relativist ontological position would enable me to construct meaning, and a rich understanding (Braun and Clarke, 2013; Carnevale, 2020) about what the home and life at home with medical technology is like for different family members.

3.2.4 Epistemology

Epistemology concerns the way in which knowledge about reality is captured or known (Lincoln and Guba, 1985; Edirisingha, 2012; O'Gorman and MacIntosh, 2015). Those with a relativist ontology and a subjective and interpretivist epistemology such as I hold for this study, talk to people (Killam, 2013) and focus on the subjective meanings that they create about their world (Orlikowski and Baroudi, 1991; Lincoln and Guba, 2005) to interpret their realities (Braun and Clarke, 2013; Carnevale, 2020), and gain an 'in-depth understanding of their stories and

contexts' (Killam, 2013: no pagination). They examine the parts and the totality of each person's situation to understand what is happening (Killam, 2013; O'Gorman and MacIntosh, 2015; Carnevale, 2020). Interpretivist researchers do not seek generalisation of the data, but seek a time and context bound (Edirisingha, 2012; Braun and Clarke, 2019), relativistic, deep understanding and interpretation of subjective meanings and experiences (Guba, 1990; Orlikowski and Baroudi, 1991; Edirisingha, 2012). Taking a subjective, interpretivist perspective was the best way to capture reality about the perceptions of 'living subjects', who each experience their place and time in the world in a different way (O'Gorman and MacIntosh, 2015: 56). Having a relativist ontology means that I believe that people create reality through dialectical processes and social interaction. I believe that the only way to construct meaning about my participants' realities that are influenced by experiences (Edirisingha, 2012) in time, place and culture (Howe, 2009), is through human communication and understanding (Grix, 2010). My interpretivist epistemology is one in which I believe that the only way to construct meaning (Silverman, 2006; Thompson, 2006; Bryman, 2012) and new knowledge (Grix, 2010; Nevo and Slonim-Nevo, 2011; McLaughlin, 2012) about my research topic is through engaging and interacting with participants in an empathic, holistic, empowering and inductive way (Rodwell, 1998; Caelli, Ray and Mill, 2003; Grix, 2010; Carnevale, 2020).

3.2.4 Summary of the Methodology Section

In summary, I believe that the best way to generate, interpret and understand the subjective experiences of children and their family members about how medical technology impacts upon their home and life at home was by using a generic qualitative methodology and taking a holistic, person-centred and inductive approach to my engagement *with* them. The selection of the data collection and analysis methods will now be discussed.

3.3 Research Design

Auto-driven photo-elicitation interviews and semi-structured interviews were the two methods chosen for this study. In the following section I present the rationale for choosing these methods. I then outline the sampling strategy, the inclusion and exclusion criteria, patient and public involvement, gaining ethics approval, and the recruitment of participants to the study. Legal and ethical responsibilities and considerations regarding participant and researcher wellbeing, consent and assent, protection of confidentiality, anonymity and privacy, and the management and storage of data are interwoven throughout this section. Working reflectively (reflecting *on* practice after the event), and reflexively (reflecting *in* action) is a requirement for any researcher role (Vitae, 2018a) and has been important throughout my study and is interwoven throughout this chapter.

3.3.1 Auto-Driven Photo-Elicitation Interviews

The qualitative method of auto-driven photo-elicitation (PE), rather than researcher-driven PE interviews were chosen as the main method for this study. It is worth noting that some authors suggest that PE is a methodology rather than a method (Guillemin and Drew, 2010; Soaita and McKee, 2020) but in this study I position it as a method. Auto-driven (also known as participant-generated) PE is a method that involves the participant taking photographs and their photographs then being used as a stimulus for conversation during an interview (Epstein et al., 2006; Bryman, 2012; Papaloukas, Quincey and Williamson, 2017). The PE method was chosen for four overarching reasons. The first reason was because I had thought about my own positionality and the positioning of participants and PE is an inductive and empowering way of giving a voice to vulnerable and less heard people (Aurini et al., 2016). It is a method that would allow me to work in a collaborative way *with* each participant to try and address the power-related challenges that can occur between the researcher and participant during data generation and the potential impact on participants' emotional wellbeing. The second reason for choosing the PE method was that it would generate rich data to enable me to gain an understanding of the participants' perceptions and experiences and to construct a sense of how technology impacts upon the physicality, sense and meaning of home. The third reason was that the PE method is an established method within health and social sciences (Gibson et al., 2013; Papaloukas, Quincey and Williamson, 2017); it is a method that has been used since 1957 (Collier Jr., 1957). The final reason was that PE is a method 'located within a constructivist and interpretivist paradigm' (Woolhouse, 2019: 5). As such, it is a method that aligns to, and is compatible with a relativist ontology, subjective and interpretivist epistemology and generic qualitative methodology (Percy, Kostere and Kostere, 2015).

Involving children and young people in research is not always easy. The quality of data depends upon children being 'responsive and engaged in the research process' (Cappello 2005: 171). PE is a suitable method for engaging children and young people (Clark-Ibáñez, 2007; Gibson et al., 2013) in a meaningful, rather than tokenistic way (Carter and Ford, 2013). The PE method has been used worldwide with children and young people of all different ages (Clark-Ibáñez, 2004, 2007; Hall et al., 2007; Mandleco, 2013; Mills and Hoeber, 2013; Phelan and Kinsella, 2013; Leonard and McKnight, 2015), and abilities (Cappello, 2005; Lorenz, 2011; Dunne et al., 2017b). PE has been used with children with acute and chronic medical conditions (Castor et al., 2018) such as cancer (Epstein et al., 2006; Castor et al., 2018), lung disease or heart disease (Castor et al., 2018), renal failure (Wells, Ritchie and McPherson, 2012) as well as children using home mechanical ventilation (Israelsson-Skogsberg et al., 2018). It is a method that has also been used with siblings of children who have a disability or complex health care needs (Peddar, 2013; Castor et al., 2018) and with parents of children

who have complex health or technological care needs (Woodgate et al., 2015; Castor et al., 2018). Children and young people are reported to enjoy and engage readily with PE research (Wells, Ritchie and McPherson, 2012; Peddar, 2013).

PE is a method that is seen to give a voice to people who are socially excluded (Papaloukas, Quincey and Williamson, 2017) and whose views are often disregarded 'from policy or other kinds of decision making' (Aurini et al. 2016: 85). PE is a useful method to reduce the imbalance of power between the researcher and the participant (Clark-Ibáñez, 2007; Mandleco, 2013; Leonard and McKnight, 2015; Soaita and McKee, 2020), including child participants (Clark-Ibáñez, 2007; Hall et al., 2007; Peddar, 2013; Leonard and McKnight, 2015), as the participant has 'greater control over the conversation, and (can) feel that their thoughts are valued' (Briggs et al., 2014: 160-161). PE is a method that can reduce participants' feelings of being interrogated by the researcher (Banks and Zeitlyn, 2015), having to maintain eye contact with the researcher (Banks and Zeitlyn, 2015; Leonard and McKnight, 2015) and having to answer the researcher's questions correctly (Leonard & McKnight 2015). The participant knows the story behind their photograph, which provides a visible prompt that can both trigger their memory (Epstein et al., 2006; Briggs, Stedman and Krasny, 2014; Ford et al., 2017) and enable them to understand their world more fully (Mandleco 2013). The photographs can be used to enhance descriptive and meaningful language (Epstein et al., 2006; Briggs, Stedman and Krasny, 2014; Ford et al., 2017). This is especially helpful for those who may otherwise find it difficult to articulate their experiences (Ford et al., 2017), such as people with cognition or communication difficulties (Lorenz 2011), and children, who may communicate differently to adults (Carnevale, 2020), or whose communication can be 'limited by vocabulary, development, (and) memory' (Cappello 2005: 170). This is especially important for people who are not usually encouraged to articulate their thoughts or take part in decision making or research (Mandleco 2013).

PE is a useful method for enhancing rapport and lessening discomfort (Hall et al., 2007; Briggs, Stedman and Krasny, 2014; Soaita and McKee, 2020), enabling adults (Harper, 2002; Lorenz, 2011; Mandleco, 2013) and children (Epstein et al. 2006) who may have difficulty in trusting and opening up to the researcher to be more expressive and to discuss abstract ideas to document their life. PE is a useful way of making the interviews fun for children and to facilitate communication, especially if a child has taken [or directed the taking of] the photograph themselves, so has 'awareness and knowledge about the photo' and its story (Briggs et al. 2014; Hall et al. 2007: 2.5.5), because photographs do not tell the whole story (Pyle, 2013; Leonard and McKnight, 2015; Papaloukas, Quincey and Williamson, 2017; Williamson, 2018).

Auto-driven PE method is reported to take the researcher into the world of their participants (Pink, 2015). This can enhance the researcher's understanding of their participants' lived experiences and subjective narratives (Nevo and Slonim-Nevo, 2011; Dunne et al., 2017a; Papaloukas, Quincey and Williamson, 2017). As such, I hoped the photographs would provide a meaningful context for discussion (Bryman, 2012) to bridge the gap between the participants' worlds and my world (Harper 2002). By triggering memory about taken for granted settings and objects (Bryman, 2012) and enabling participants to share abstract ideas and stories about their lives, I hoped to gain a deeper, richer insight into, and understanding and interpretation of, each participant's human experience and subjective narratives than if I used interview methods alone, as recommended by other researchers (Epstein et al., 2006; Bugos et al., 2014; Papaloukas, Quincey and Williamson, 2017). Furthermore, I hoped to see, hear and understand thoughts and experiences that other researchers say might otherwise have remained suppressed, concealed or misunderstood if auto-driven photographs had not been taken (Harper, 2002; Clark-Ibáñez, 2007; Mandleco, 2013; Bates et al., 2017).

3.3.2 In-Depth Semi-Structured Interviews

In-depth semi-structured interviews were an option for participants who did not wish to or could not take photographs. The semi-structured interview method was chosen for the same four overarching reasons as PE interviews. The first reason why the semi-structured interview method was chosen was because, like PE interviews, it is a participatory and collaborative method that places an emphasis upon the participant (Hardwick and Worsley, 2011; McLaughlin, 2012) and affords them a lot of flexibility in how much or how little they share about their perspectives and experiences (Bryman, 2012; Wahyuni, 2012; Bowling, 2014). Participants are able to provide full opinions (Bowling, 2014) when they so wish, but still remain in control of the interview (Grix, 2010) by being able to talk about what they consider to be the most important issues (Bryman, 2012), thereby addressing some of the power-related challenges that can occur between the researcher and participant during data generation.

The second reason for choosing the semi-structured interview method was that it would generate 'rich and quotable' data (Bowling, 2014: 279) to help me to gain an in-depth understanding of each person's diverse and complex, yet subjective, perceptions and experiences (Polit and Beck, 2009; McLaughlin, 2012; Wahyuni, 2012). Semi-structured interviews are a method that afford an experienced researcher like myself some degree of flexibility, enabling me to ask open ended questions in an unspecified order, to probe more fully, and pursue any unexpected avenues of enquiry during the interview (Grix, 2010; Bowling, 2014). The semi-structured interview method allows the researcher to check any inconsistencies or misinterpretation (Irvine, Drew and Sainsbury, 2012; Bowling, 2014), or any

idiosyncratic or literal use of language that might otherwise be incomprehensible (Vogl, 2015). It is a method that gives the researcher insight into 'social cues, such as voice, intonation and body language' (Opdenakker, 2006: no pagination). The third reason was that the semi-structured interview method is a prominent and established method within health and social sciences (Bryman, 2012; Bowling, 2014). The fourth reason was that it is a method that is compatible with my ontology and epistemology, and the methodology that underpin this study (Percy, Kostere and Kostere, 2015).

In conclusion, auto-driven PE and semi-structured interview methods are suited to the ontology and epistemology underpinning the chosen generic qualitative research methodology and are appropriate to answer the research question. Importantly, they are inductive and participatory methods that can be differentiated to the participants' needs.

3.3.3 Sampling Strategy

As shown in the overview of recruitment process (Appendix 8), purposive and snowball sampling were the approaches adopted for this study. Purposive sampling is when participants must have a particular characteristic or characteristics and the necessary experiences to generate data that will answer the research question (Bryman, 2012; Wahyuni, 2012; Bowling, 2014). The specific characteristics required for this study are detailed in the inclusion criteria (Table 3.1). Family members were able to take part even when the technology-dependent child, young person or adult did not wish to or was unable to communicate or provide assent, provided that the inclusion criteria were met. In the case of a technology-dependent child or family member being a child or young person under the age of 16, they needed to have an adult who could provide consent for them.

Snowball sampling (non-probability sample) is when the researcher initially makes contact with a small number of relevant potential participants, and then uses these participants to contact other relevant participants (Bryman, 2012). As snowball sampling can be an effective way to recruit vulnerable or small populations (Bowling 2014), it was considered an ideal approach to recruit participants to this study because families who have technology-dependent children often know other families who have a technology-dependent child.

Table 3.1 Inclusion and Exclusion Criteria for Participants

Inclusion Criteria
Aged 5-25 years with a medical condition (i.e. the project is not condition specific) that causes them to use at least two pieces of medical technology, to monitor and treat their medical condition or sustain their life, and have used this technology for at least three months, at home in the North West of England or:
Parent (or a relative aged at least 5 years old) of a child, young person or young adult who meets the above criterion. If the parent or relative did not live with or care for the child, young person or young adult in their own home, they must have provided some care for them in their home for at least three months.
Can speak/understand English sufficiently fluently to be able to tell me what life with medical equipment at home is like (using Augmentative and Alternative Communication (AAC) aids where necessary).
Can give informed assent/consent (note: parental consent was also obtained if the participant was under the age of 16).
Live in the North West of England.
Exclusion Criteria
Any person who did not meet the above inclusion criteria.

The minimum age of 5 years for participants aligned with Vogl's (2015: 319) findings 'based on 112 semi-structured interviews with children aged 5-11 years' that interviews can be conducted with 5-year-olds if researchers are prepared to accept the limitations in their 'verbal, interactive and cognitive skills'. The minimum age of 5 years also aligns with the age of children who participated in the studies included in the integrative literature review (Levine, 2005; Earle et al., 2006; González et al., 2017; Castor et al., 2018). Also, the minimum age of 5 seemed appropriate in terms of using PE and semi-structured interviews; these methods support children's cognitive and communication competencies and enable them to share their ideas with me (Harper, 2002; Morrow, 2008; Lorenz, 2011; Mandleco, 2013).

The rationale for the maximum age of 25 years for technology-dependent children and young people to take part was because the Children Act 2004 (HM Government, 2004) and Children and Families Act 2014 (HM Government, 2014b) legislate that when a person aged under 25 needs 'more support than is available through special educational needs (and disabilities - SEND) support', they are included in the reference to a child, in addition to a person under the age of 18 (HM Government, 2018a). The rationale for children requiring at least two pieces of medical technology reflects complexity of need. The rationale for the children requiring their technology for at least three months was to give participants the opportunity to become familiar with living with technology and to have experience of how this had impacted upon their home and life at home.

The rationale for including wider family members, such as grandparents, aunts and uncles, was because the challenges of caring of a technology-dependent child can negatively impact upon the health and wellbeing, family functioning and quality of life of the whole family, including extended family members. I knew from conducting previous research (Mitchell et al., 2016) and from the integrative review that wider family members, such as technology-dependent children and their siblings and grandparents, are an under-researched population and I wanted to ensure that their voices were represented in this research.

I hoped that 10-15 families would be recruited through children's charities and hospices. I anticipated that a total sample size ranging from 10-24 participants would be generated, depending upon the number of technology-dependent children and immediate and wider family members who participated (for example, one or more siblings, one or both parents, one or more grandparents, aunts or uncles). This anticipated sample size of 10-15 families was generated based on due consideration of the target population. The number of families eligible to take part in the study would be relatively small and it was clear from the literature review that I would potentially find it difficult to recruit technology-dependent children because of their cognitive difficulties. Only nine out of 33 empirical studies included in the integrative review had included the children or young people with complex health care needs. I appreciated that the required sample size is dependent upon the study question, the quality of and amount of data, and the researcher's ability to be reflexive (Morse, 2000; Thorne, 2008; Creswell and Poth, 2017; Denzin and Lincoln, 2017). I was confident that my selected methods would allow me to gather sufficient high-quality data, even with a relatively small sample, to develop a deep, rich understanding of how medical technology impacts the home and life at home. Cooper and Endacott (2007) report that sample sizes of between five to 20 participants can be sufficient, whilst Soaita and McKee (2020) state that sample sizes of over 20 participants are rare for auto-driven PE interview studies.

3.3.4 Patient and Public Involvement

Patient, service user, carer and public involvement in research aims to ensure that the people who will be most affected by the study recommendations can contribute to developing the study design, recruitment and interview materials. This is important to ensure that the study is accessible and that the findings and recommendations are relevant for the delivery of high quality services and support (National Institute for Health and Care Excellence, 2013) that support the people who are most affected (Involve, 2020).

The UN Convention on the Rights of the Child (1989) establishes the right of every child to 'express their views, feelings and wishes in all matters affecting them, and to have their views

considered and taken seriously' (Article 12). It is important to take 'positive action' (HM Government, 2010), as defined in the Equality Act 2010, to purposefully involve and listen to technology-dependent children and their family members who are frequently overlooked.

As recommended by Lambert and Glacken (2011), I wanted to be sure that the terminology used in my recruitment and interview materials would be understood and acceptable to children and their families. I felt that this would increase accessibility for potential participants and would enhance their ability to make an informed decision as to whether to take part in the study or not. All written communication for participants used size 12 Arial font and left justified text to support the National Accessible Information Standard (NHS England, 2017: 16). This is the format that is most suitable for participants who have a specific learning disability such as dyslexia as well as being one of two suitable fonts for children (British Dyslexia Association, 2011). I also wanted to ensure that the recruitment materials would be aesthetically appealing to any potential participants. I created the study flyer, invitation letter, participant information sheets, consent and assent forms and interview schedules (Appendices 11-30), using the knowledge and experience that I had gained from my previous roles and the literature review gaps, and then shared these recruitment materials with my supervisory team to draw upon their knowledge and experience. My supervisory team recommended that I increase the amount of white space on the forms so that they were more readable. Then, before submitting my application to Edge Hill University Faculty of Health and Social Care Research Ethics Committee (FREC) with the appropriate documentation (Appendix 10), I consulted with the Together for Short Lives Research Reference Group, families at conferences and parents on social media to check the readability and accessibility of my recruitment materials (study flyer, invitation letter, participant information sheets, and consent/assent forms (for all categories of participant) and interview schedules). Feedback was positive: 'The colours are good' and the information sheets 'answer the questions in clear language'. As recommended by two families, however, the word 'technology' was changed to 'equipment' in any research documentation shared with the children and their family members.

In the months following submission of the thesis I plan to involve families via the Together for Short Lives Research Reference Group and the Edge Hill University Service User and Carer Council in helping me to find effective and sensitive ways of disseminating the findings of this study.

3.3.5 Gaining Ethics Approval

The dignity, rights, safety and well-being of participants must be the primary consideration in any research project and must take precedence over the research project in accordance with the Declaration of Helsinki 2013 (World Medical Association, 2018). My whole research approach guided me to explore human experience in a collaborative way, whilst promoting the participants' wellbeing and ensuring equity and equality. This approach is highly compatible with the five ethical principles of researchers: beneficence (do good/the right thing), non-maleficence (do no harm); justice (be fair); autonomy (independent); and veracity (be completely truthful) (Guillemin and Gillam, 2004; Lambert and Glacken, 2011).

All standard professional, organisational, national and international legal and ethical frameworks and principles were followed with regard to participant and researcher wellbeing, recruitment, consent, data collection, the protection of confidentiality, anonymity and privacy and the management and storage of data (HM Government, 1998b, 2010, 2018c, 2018b; Universities UK, 2012; NHS Health Research Authority, 2013, 2017b, 2017a; World Medical Association, 2018).These issues are dealt with in the relevant sections later in this chapter.

All required documentation listed in Appendix 10 (Appendices 9-30), including the data management plan[12] (Appendix 9), were then submitted to Edge Hill University Faculty of Health, Social Care and Medicine Research Ethics Committee (FREC) for ethics approval before the study could commence. This included a copy of the emails (20th March and 3rd April 2017) from Together for Short Lives who had agreed to advertise the study once ethics approval had been granted. NHS Health Research Authority approval was not required as participants were not recruited via either health and social care environments or professionals working with a child or their family members. Edge Hill University FREC requested information sheets and consent/Personal Consultee (likely to be the technology-dependent adult's parent) declaration forms for any technology-dependent adults aged 16-25 years who might not appear able to decide for himself/herself whether to participate in this research study.

Therefore, after re-familiarising myself with the Mental Capacity Act 2005 and checking the guidance on the NHS Health Research Authority (HRA) website (NHS Health Research Authority, 2017b), two further information sheets, a consent form for Adults who have a

[12] The data management plan provided a detailed description of how data would be collected and processed in an fair and lawful way, adhering to legislation and guidance (HM Government, 2018b, 2018c) and the University's Research Data Management Guidelines which govern the disclosure, sharing, storage and destruction of information.

Personal Consultee[13], and a Personal Consultee Declaration form (Appendices 15, 17, 22, 25) were created and submitted to FREC. Written approval for the study was granted by Edge Hill University FREC on 27th June 2017 (FOHS 171) (Appendix 31).

Two amendments were made in relation to permission to recruit participants. The first amendment was for recruitment through the Edge Hill Service User and Carer Council (approved on 4th August 2017) (Appendix 32). The second amendment was to recruit participants from anywhere in the United Kingdom and to be able to conduct telephone or online interviews instead of face-to-face interviews where requested by participants or for pragmatic reasons (approved on 28th March 2018) (Appendix 33). An additional information sheet was created as a result of the changing General Data Protection Regulation (GDPR) requirements (25th May 2018) (Appendix 34).

3.3.6 Recruitment Procedure

After receiving written ethics approval, I initially adopted a staged approach to recruitment to allow time to review the interview technique before moving forward to recruit further participants (Appendix 8). I started recruitment in July 2017, via Together for Short Lives[14] who had already agreed to advertise the study once I had completed their 'Call for Participants for Research Form' and had submitted evidence of ethics approval. I then contacted the Administrator of the Edge Hill University Service User and Carer Council after receiving ethics amendment approval in August 2017, followed by the Management/Board of Trustees of WellChild[15] to explain the purpose of the study and ascertain whether they were willing to advertise the study flyer (Appendix 11) via email, their own website or their social media pages.

After reading the study flyer, potential participants contacted me via their preferred method (my University email and telephone number were provided on the flyer; no participants used my postal address) to ask questions and/or confirm their/their child's interest in taking part in the study. They were then sent an invitation pack (invitation letter, study flyer, the relevant

[13] A Personal Consultee is a person who is 'engaged in caring for the participant [who lacks capacity] (not professionally or for payment) or is interested in his/her welfare, and is prepared to be consulted' to advise on what the person's wishes or feelings would be about taking part in the study (NHS Health Research Authority, 2020).
[14] Together for Short Lives are the leading UK charity for children who are expected to have short lives.
[15] WellChild are a charity whose 'vision is for every child and young person living with serious health needs to have the best chance to thrive - properly supported at home with their families'.

participant information sheet(s) and consent/assent form(s) (differentiated to the participant's age, developmental stage and/or cognitive ability, and whether they used medical technology or were the family member/carer of a child who used medical technology). The forms for adults with a personal consultee and personal consultees were not required as no participants had a cognitive impairment that caused me to believe that they were unable to decide for themselves whether to participate in this research study or not. I contacted potential participants again one week after sending the information pack, if they had not contacted me in the meantime, to ascertain whether they still wished to participate, and to answer any of their questions. I made no more than three attempts to contact the family, as I did not want to be a burden, or for them to feel pressure to take part in the study. I kept a record of any attempts to contact a family. Along with written information, all participants were also given verbal information about the study to ensure that they fully understood what the study was about, why it was being done and what it would involve, in accordance 'with relevant legal frameworks and ethical principles' (HRA, 2017).

The participant information sheets detailed that a child and/or family member had the option of using their own device/s (phone/camera/tablet), or of borrowing a camera to take/direct the taking of photographs. The sheets stated that participants could choose to take photographs about their life with medical equipment/technology at home. Instructions were also given verbally whilst arranging a convenient date to conduct the auto-driven PE interview 1-2 weeks later. I established which method (electronically or via personal contact) the participant would prefer for transferring their chosen (up to) 15 photographs to me so that I could print them before the interview, and arranged a convenient date to conduct the auto-driven PE interview 1-2 weeks later. The rationale for transferring only up to 15 photographs was to try to ensure that the interviews would not be too time-consuming for the families and would be focussed enough to answer the research question.

I had planned to deliver cameras to people who wished to participate but who did not wish to use their own device/s, but this was not necessary as all participants used their own devices (iPad/tablet/mobile phone).

By November 2017, four months after commencing recruitment, only three families had taken part in the study. I had anticipated that recruitment might be slow or unsuccessful through the above organisations (despite Together for Short Lives and WellChild being national charities) and knew I might need to recruit through further charities, hospices and organisations detailed in Table 3.2. I knew from previous experience in research and student roles (and the slower recruitment through Together for Short Lives, Edge Hill University Service User and Carer

Council, and WellChild) that recruitment is near impossible in late November and December, prior to and around the Christmas period, so I waited until early January 2018 to contact the Management/Board of Trustees of Claire House Children's Hospice, with whom I had an existing relationship. Claire House Children's Hospice agreed to advertise the study, and the same procedures were followed as detailed above. I reflected about what else I could do to mitigate the fact that recruitment was slower than anticipated. I had initially planned to recruit participants only from the North West of England as I had no funding for travel. However, because participants from outside of the North West of England had expressed an interest in taking part in the study, I made the decision to open the study up to include participants from anywhere in the United Kingdom (UK). Some potential participants had expressed a desire to take part in a telephone interview. I submitted an ethics amendment to recruit participants from anywhere in the UK and to be able to conduct telephone interviews in addition to face-to-face interviews (Appendix 33). Following approval (March 2018), I identified the appropriate key contact of other third sector charity organisations and children's hospices in the order shown in Table 3.2 to ascertain whether they would be willing to advertise the study by email or via their social media and website pages and then followed the same processes as above.

Table 3.2 Names of charities, hospices and organisations contacted

Together for Short Lives
Edge Hill University Service User and Carer Council
WellChild
Claire House Children's Hospice
Derian House
Grace's Place (ForgetMeNot)
Brian House and Trinity Hospice
Rainbow Trust Children's Charity
BreatheOn UK
Hospice UK
Roald Dahl's Marvellous Children's Charity
Twinkle House, Skelmersdale
Person Shaped Support, Liverpool
Genetic Alliance, SWAN

Hospice UK required a research proposal summary and some content for their monthly newsletter, whilst Brian House and Trinity Hospice required a research proposal and my curriculum vitae. In a similar way to how I contacted participants, I was systematic in my approach to contacting charities and hospices and kept records of my contacts with them as a way of mitigating the risk of staff in these organisations feeling harassed or burdened. Charities and hospices were contacted a maximum of four times.

Potential participants contacted me via their preferred method to ask questions and/or confirm their own/their child's interest in taking part in the study after reading the study flyer (Appendix

11). In total 21 mothers and 2 fathers (n=23 parents) expressed an interest in taking part in the study, but two mothers and one father did not meet the eligibility criteria because their child was either too young, had died, or had moved into residential care. Twenty families were sent the invitation pack, which comprised of an invitation letter, participant information sheet(s) and consent/assent form(s).

3.4 Data Generation

In this section of the chapter I will outline how I conducted the face-to-face and telephone PE or semi-structured interviews. Throughout the section I will consider communication methods and ethical considerations to do with participant and researcher health and wellbeing, confidentiality, anonymity and privacy and the management and storage of data.

3.4.1 The Interview Setting

Being flexible about the timing and location of the interview is an important aspect to consider as the quality of the data can be affected by whether the participant feels comfortable enough to speak (Epstein et al., 2006). I ascertained the best time for child participants (when they would be most alert/least tired), and the time that most suited the family routines when arranging the interviews with parents. All participants who had chosen to participate in face-to-face interviews (PE or semi-structured) requested that the interview take place in their home, although additional options were offered, for example, another person's home, a coffee shop, or in a private room at Edge Hill University. All participants who took part in PE or semi-structured telephone interviews were also in their home at the time of their interview. The reason for choosing to be interviewed at home could have been because home was their own territory, a familiar place where they felt most comfortable, as reported by other researchers (Epstein et al., 2006; Coad et al., 2015; Israelsson-Skogsberg et al., 2018). Another important consideration was that by being at home, participants did not have to travel (Coad et al., 2015) and the technology, equipment and resources required for their child were to hand.

I adhered to the Safe Fieldwork protocol (Evidence-based Practice Research Centre, Edge Hill University) and used my past social work experiences to minimise or mitigate the risks of interviewing in family homes. Procedures such as having a 'buddy support system' were in place to deal with lone working when conducting face-to-face interviews.

Participant and family wellbeing took precedence over the research study and was always paramount. As technology-dependent children are more susceptible to infection, I used a hand sanitiser whilst still in the car before entering the family home to reduce the risk of transferring germs to protect the children and their family members. If I had been unwell, I would not have

conducted an interview. Furthermore, some dyad interviews occurred (e.g., when a child or young person required health or communication support) even though I was aware that having another person or people in the room could have limited privacy and the completeness of accounts. I used my experience in managing family dynamics to ensure that the participant (child, sibling or parent) remained at the centre of the interview.

After introducing myself and reminding participants what the study was about, I offered the opportunity to ask questions and reminded them of their right to withdraw from the study. I asked telephone interview participants to ensure that they were in a comfortable and private place in their home. I asked face-to-face interview participants which room they would like their interview to take place in, following safeguarding practices to ensure that I did not put myself in a position of being alone with a child in any room with a closed door. Some participants wanted to show me around the downstairs of their home. When this was their preference, and with their permission, I would move around the home with them to see the different pieces of medical technology, before coming back to the participant's preferred room. With their permission I recorded the conversation we had whilst they were showing me around.

3.4.2 Gaining Consent and Assent

All participants were advised that I would maintain confidentiality of their personal data and would adhere to organisational (EHU Data Management Guidelines), professional (HCPC Standards of Conduct, Performance and Ethics) (Health & Care Professions Council, 2016), and national and international legislation and guidance at all times (HM Government, 2018b, 2018c; NHS Health Research Authority, 2018).

Careful consideration of the potential for identifying participants took place. This took account of the photographs, the small sample size, and the relatively small target population. The ethical principle of non-maleficence (Guillemin and Gillam, 2004; Lambert and Glacken, 2011) cannot be guaranteed if participants can be identified. Participants were reminded of the risk that they/their family could be identified by people who know them/their family's home or the technology, particularly if they agreed for photographs to be used in dissemination. This risk for anonymity was highlighted to participants in the information sheet, on the consent or assent form and throughout the interview. Although adult participants were happy to waive their right (and their child's right) to anonymity, I still wanted to take every step to mitigate the risk for their anonymity by limiting the information provided to the reader. For example, specific details about the child's diagnosis and unique details about the family are not included in interview

transcripts, this thesis or dissemination materials. Furthermore, pseudonyms[16] have been used when transcribing the audio recording of the interview and in dissemination materials in case other members of their family were later uncomfortable about people knowing that someone from their family had participated in the study. Although full consent was given for the use of photographs in any form of study dissemination, participant identifiers are not ascribed to the photographs which are presented in the Picture Gallery (Section 4.3.2). Quotations in the photograph captions might be from a different family to the one who shared the photograph. Age range brackets of 5-10 years, 11-15 years, 16-20 years, and 21-25 years were assigned for all children and siblings to reduce the risk of breaching anonymity. I was the only person with direct access to identifiable raw data. Although Research Councils (RCUK) Common Principles on Data Policy (2015, updated July 2018) states that data should be made openly available, and that traditional confidentiality should be balanced with contemporary openness, the decision was made that it was not appropriate to share the anonymised raw data for this study beyond my supervisory team.

A statement was included in the participant information sheets about disclosure. Participants were reminded before starting the interview that I could not sustain confidentiality if there was a verbal or photographic disclosure that a person had been harmed or was at risk of harm, in line with appropriate legislation and guidance (HM Government, 1989, 2014a, 2018d). Confidentiality was not breached as there were no disclosures of harm or risk of harm.

I asked all participants whether they wanted me to read their information sheet to them. This was a final check to ensure that they had the appropriate information to make an informed decision as to whether to take part or not. By ensuring that participants understood the potential risks and benefits of taking part in the study, I could be as assured as possible that the participants were taking part freely, had the capacity to consent/assent, and had not been coerced or unduly influenced (Hardwick & Worsley 2011; Guillemin & Gillam 2004). Participants had the opportunity to ask questions before I then read the consent or assent form to them, gained consent or assent and the interview commenced.

Separate consent and assent processes were followed as relevant, using communication aids when necessary. Using reasonable and non-exploitive procedures to gain meaningful,

[16] Pseudonyms were assigned for all participants alphabetically (A-J), in the order of participation, except for one child and one sibling who decided their own pseudonym ('Monkey', Child in Family 3 and Ruby, Sibling in Family 1).

informed consent and assent (Oulton et al., 2016) was particularly critical in this study due to some participants being vulnerable[17]: one sibling was under 16 years old; one of the two young people with health and technological care needs and communication difficulties was under 16 years old and had disabilities; the other person with health and technological care needs and communication difficulties was an adult but had disabilities. These three participants required reasonable adjustments, such as simplifying communication or using Augmentative and Alternative Communication devices (AAC) (discussed in 'The Interview' Section 3.4.4). I used good observation skills to identify whether they were becoming tired or bored, or needed a break, to participate in this study.

Although it is not a legal requirement to obtain a child's assent (Gibson and Twycross, 2007), gaining children's informed assent is a crucial part of child-centred research (Lambert & Glacken 2011). Oulton et al. (2016) recommend that the youngest age that assent should be gained is three years old. The youngest person to participate in this study was in the 5-10-year-old age bracket. Ongoing consent or assent for all participants was not assumed until the 8th day after the interview, so that they could exercise their right to withdraw from the study after their interview. The rationale for this timescale was that data analysis may have commenced after this time.

All participants gave permission for me to digitally audio-record their interview and were informed that they could stop, pause or postpone the interview at any point. Any reference to the sharing or storage of photographs, and the use of photographs being kept for comparison in my future studies on the consent or assent forms (Appendices 20, 21, 23 and 24) was scored out if a participant did not take photographs. PE interview participants gave informed written consent (or audio-recorded verbal consent for telephone interviews) for me to use all their photographs in all forms of dissemination materials and future studies. All participants (and the person with parental responsibility if the participant was a child) gave written consent (or verbal consent, for telephone interviews) to the use of direct quotations from the interview data in my thesis, presentations, publications and future studies.

Pseudonyms were assigned for all participants alphabetically (A-J), in the order of participation, except for two children who chose their own pseudonym (Ruby, Sibling in Family 1 and 'Monkey', Child in Family 3).

[17] Some participants were vulnerable due to having some of the nine protected characteristics under the Equality Act 2010 (HM Government, 2010).

3.4.3 Data Management

Participants transferred their photographs to me via email to my password-protected encrypted university Microsoft Office email address prior to and during their PE interview. Edge Hill University's IT Department confirmed that this was a secure method of data transfer for the photographs. I stored the photographs on the Edge Hill University network, which is encrypted, and password protected in accordance with the Data Protection Act 2018 (HM Government, 2018b), which supersedes the Data Protection Act 1998 (HM Government, 1998a) and implements the General Data Protection Regulation 2018 (Appendix 34). The audio-recording of the interview and scans of any paper versions of, for example, participant contact details, consent and assent forms were transferred into and stored electronically on the University drive. The paper versions were destroyed via confidential waste at the University as soon as possible after the interview. All electronic devices such as my home computer and mobile phone (on which I can access my EHU emails) are password protected. Participant contact details, consent and assent forms and audio files were stored separately from other research data. Audio recordings were destroyed at the end of the study rather than when the interviews were transcribed and checked for accuracy, to be able to listen to them more than once to check a participant's tone and my interpretation whilst analysing the data and writing the findings and discussion chapters. I was the only person to know what each participant said, as I conducted and transcribed the digitally recorded interviews myself.

As well as being stored on the University network, the photographs and anonymised transcripts were also stored within my password protected NVivo account (QSR), which is the software package that was used for data management and analysis. QSR do not collect any details of the data.

3.4.4 The Interview

Participants from five families took part in face-to-face interviews, whilst the participants from the other five families took part in telephone interviews. All interviews, including PE interviews, followed a semi-structured interview format. All participants (including telephone PE interview participants) were at home at the time of their interview. Telephone interview participants were offered the option of a video call (using Skype, for example), but all declined this alternative option.

All interviews began with a period of free narrative about general daily life, which helped the participant and I to develop rapport. Free narrative at the beginning of the interview is especially important for children to enable them to settle into the interview (Fargas-Malet et al., 2010). Parents all began their interviews with a chronology of their child's medical

condition(s), health care needs and life. This was helpful as it provided me with some context about their child's need for medical technology and the order in which it was introduced. As shown in Table 4.1 in the next chapter, parent interviews took place before the two interviews of the children (and one sibling) who were under 16 years old (although parents were still close-by for their children's interviews).

Photographs for the face-to-face photo-elicitation interviews had been printed for use in the interview, whereas photographs for telephone photo-elicitation interviews (all with adults) were copied into a Word document, 6 photographs to an A4 page, and numbered. This document was emailed to the participant before their telephone interview, so that they could tell me which photograph they were referring to during their interview. Participants taking part in PE interviews were then asked to choose which photograph they wished to start with. They were asked why that photograph was important to them/how that photograph represented their life with medical equipment at home. Participants taking part in semi-structured interviews were asked which piece of technology they would like to discuss first. All participants then chose which photograph or piece of technology they would like to discuss next and I followed the order that they wanted throughout the interview.

Although an interview schedule was used (Appendix 26-30), this was not used in a prescribed or rigid way as I wanted to avoid what Thomas and Woods (2003) talk about in terms of impeding the natural flow of conversation. I followed the participant's lead and had questions and photographs interspersed. The interview schedule, like the participant's photographs, was a useful tool to counteract the power associated with my role, and as reported by Collins et al. (2016), it also helped to maintain the flow of the interview and return to relevant avenues of enquiry when a participant went off topic or when the flow of the interview was interrupted by people coming into the room, or their telephone ringing. As mentioned by Epstein et al. (2006) and O'Reilly and Dogra (2016), a drawback of using the home as an interview location is that these types of interruptions can disrupt the flow of conversation. However, I knew these disruptions would be unavoidable as parents cannot have their telephones on silent or ever be truly alone because of the immediacy of their child's health care needs.

As proposed by Fargas-Malet et al. (2010) open questions were asked. I also adopted active listening to understand the participants' experiences of medical technology in the home, whether and how the fabric of the home had been changed and the practices that facilitated the integration of technology into the home. Participants could take control of the conversation by saying as much or as little as they liked about each photograph (some participants chose to speak about only some of the photographs), adaptation or piece of technology. The

photograph enhanced collaboration (Clark-Ibáñez, 2007; Leonard and McKnight, 2015) and the flow of the interview (Israelsson-Skogsberg et al., 2018) because we both had some degree of understanding about it (Harper 2002). This also aided my interpretation. Paraphrasing was also used as a strategy to verify my understanding of the participants' accounts. I found that having some pre-existing knowledge of the challenges that family members faced from working on previous studies and conducting the literature review facilitated conversation and enhanced my understanding and interpretation.

The effectiveness of communication between the participant and the researcher can affect trust (Guillemin & Drew 2010) and this can affect the quality of the data collected (Epstein et al., 2006). Vogl's (2015: 335) findings emphasise the need for researchers to be 'well-trained, sensitive, and experienced'. I have worked with children, young people and adults who have cognitive, fine and gross motor skills or visual difficulties, and communication, social, and behavioural difficulties throughout my career. I was experienced in using AAC such as Picture Exchange Communication Systems (PECS) symbol sets, Cue Cards, as well as Social Rule Cards, Social Stories, visual aids and intensive interaction with children, young people and adults. These experiences and skills enabled me to adapt my approach by, for example, slowing down my communication, simplifying my questions, waiting patiently for children's responses and, as all child interviews were face-to-face, using good observation skills to read body language to anticipate tiredness, boredom or distress and to encourage and enhance the children's communication during their interview.

Although telephone interviews gave me access to geographically separated adult participants, a limitation of telephone interview is that it is not always possible to pick up on their non-verbal cues (Opdenakker, 2006; Irvine, Drew and Sainsbury, 2012). However, empathic, active listening enabled me to determine the emotional state of the adult participants who chose this method. Being an experienced researcher and having excellent interpersonal skills supported me to quickly learn that participants would often laugh rather than complain when they were discussing negative experiences of having adaptations to their home or living with technology. I could then check my interpretation with them. This was a finding that aligns to those of Irvine, Drew and Sainsbury (2012: 91), who state that careful listening enables researchers to draw on cues such 'as tension, anger, sarcasm, curtness, tears or rapid speech'.

I ensured that explanations and questions were clear and easily understood and remained open to all participants' language style, working at their pace and being patient, attentive and responsive to their verbal and non-verbal responses. Differentiating my communication and interview techniques, using communication aids, and being flexible about the timing and

location of the interview were some of the strategies that I used to facilitate a comfortable interview atmosphere. Other strategies were engaging in reflective and reflexive practice, and in monthly supervision with my supervisory team, which helped me to think more critically about the impact of my personal values, beliefs, biases and prior experiences and training on participants. Supervision also provided me with the opportunity to debrief due to the emotionally intense nature of some interviews. This, in turn, enhanced the study design, data collection and analysis processes, as well as the trustworthiness of the study.

My excellent communication and observation skills, and ability to differentiate these to suit the participant, were useful. As reported by Lambert and Glacken (2011) and Collins et al. (2016), having these skills enabled me to work patiently and sensitively with, and at the pace and style of children and siblings to overcome any linguistic or cognitive development difficulties and enhance their participation. They also helped me to fulfil my duty of care to the participants of this study to protect their safety, wellbeing, dignity and privacy, whilst enabling them to have their voices fully heard (Phelan and Kinsella, 2013; World Medical Association, 2018). As reported by other researchers (Bates et al., 2017; Papaloukas, Quincey and Williamson, 2017; Williamson, 2018), these skills support participants to talk about their sensitive, abstract and hard to articulate experiences. These communication and observation skills were especially important for the two young participants who were technology dependent; one used an AAC, known as a 'talker' to communicate with me during their interview. The pace of the interviews for the technology-dependent young people and the younger sibling was slower than with other participants, especially for the young person who needed time to spell out their responses on their eye-gaze computer. Using good observation skills enabled me to know when the children and young people wished to move on to the next photograph or when they were becoming tired and needed to have a break. It was exciting and I felt privileged to hear the thoughts and experiences of these children and young people who are often viewed as lacking the ability to articulate their perceptions and experiences.

I was aware that a disadvantage of using PE and semi-structured interview methods is that participants may revive distressing memories (Bates et al., 2017) and become upset when taking the photographs and/or talking to me about their experiences. However, as an experienced researcher who was perceptive to the emotional state of the participants during their interview, I aimed to ensure that I supported them to talk about their experiences and for them to be in control of the situation. All participants were made aware that they could pause or reschedule the interview for another day, end it or withdraw from the study, if they became upset. I was perceptive to the participants' emotional state throughout the interview by remaining vigilant to their body language (for face-to-face interviews), social cues such as

tears or the ‘intake and exhalation of breath, pauses and their duration’ (for telephone and face-to-face interviews), and the speed, ‘intonation’ and ‘changes in volume’ of their verbal responses (Irvine, Drew and Sainsbury, 2012: 93/91). I indicated that I was interested in what they had to say (Fargas-Malet et al., 2010) and provided sensitive encouragement for them to participate, if they wished to. I ensured that all interviews were brought to a safe close by not ending the interview on any sensitive issues or when a participant was upset, by summarising and clarifying the main points reported and by ensuring that enough time was allocated to debrief with the participant. Key to debriefing was signposting participants to support networks as necessary (Appendix 19) and spending time to listen to the participant for them to leave the interview feeling positive, rather than distressed.

3.4.5 Summary of the Research Design and Data Generation Sections

I have presented the rationale for the choice of study methods, sampling strategy, the inclusion and exclusion criteria, the data generation stages of the study and the ways I tried to remove any barriers to taking part in the study. Having patient, service user, carer and public involvement in developing the recruitment and interview materials ensured that the terminology in verbal and written information could be understood by and was acceptable for potential participants. The importance of auto-driven PE and semi-structured interview methods and of acting in an ethically responsible manner have been highlighted. The importance of using good observation and communication skills, differentiated to the participant’s individual need, to ensure the participant’s wellbeing, enhance the quality of the data and overcome the data collection challenges have also been considered. By facilitating a comfortable interview atmosphere, the PE and semi-structured interview methods supported me to see, hear and understand the participants’ subjective human experiences and emotions.

3.5 Data Analysis

Thematic analysis was selected as it is a rigorous, yet flexible data analysis method to identify patterns of meaning across a dataset that can be used in an inductive and deductive way (Braun and Clarke, 2020). Taking an inductive, reflexive thematic analysis approach where ‘coding and theme development are directed by the content of the data’, rather than by the research question (Braun and Clarke, 2020: no pagination), is congruent with my epistemology and ontology and the generic qualitative research methodology and qualitative methods selected for this study.

The seven-stage sequential, yet recursive process of coding and analysis consists of: 1) Transcription; 2) Reading and familiarisation, taking note of items of potential interest; 3) Coding – complete, across entire dataset; 4) Searching for themes; 5) Reviewing themes; 6)

Defining and naming themes; and 7) Writing – finalising themes. The first six stages of description to interpretation of the data (Braun and Clarke, 2006) was undertaken between November 2018 and December 2019. The seventh and final stage of analysis then took until May 2020, but was not *completely* finished until submission of this thesis in August 2020. I will now present how I became familiar with, codified, categorised, organised, summarised and developed themes from the data. The rigorous methods used to provide a rich and meaningful account of the data will provide evidence that my interpretation of the data is trustworthy. Trustworthiness is a primary criterion for assessing the quality of a study (Guba, 1981; Bryman, 2012).

3.5.1 Transcription (Stage 1)

I transcribed the digitally audio recorded PE and semi-structured interviews verbatim into a Word document, concurrently using the Word review feature to annotate the transcript with reflections from the interview, explanations for context and initial code ideas. To mitigate the risks for participant anonymity, despite having consent to use all forms of data in all types of dissemination materials, I redacted unique details about the family and parts of photographs and used pseudonyms when transcribing the audio recording of the interview.

3.5.2 Reading and Familiarisation with the Data (Stage 2)

I read my field notes and looked at the photographs. I then read each transcript again, at least twice, whilst concurrently listening to the audio recording again to highlight items of potential interest and to immerse and familiarise myself with the content of each interview transcript, field note and any photographs. This method gave me the space to reflect upon the emotional and interpretive properties of each piece of data.

3.5.3 Coding across the Entire Dataset (Stage 3)

The transcripts and auto-driven photographs were then imported into NVivo 11 (QSR International, 2016). NVivo is a computer-assisted qualitative data analysis software (CAQDAS) package that is designed to support the organisation and analysis of qualitative and mixed methods research data. With the exception of the demographic data that was collected at the beginning of each interview, analysis was inductive so as not to 'fit the data into pre-existing categories' (Percy et al., 2015: 80), the research question or my preconceived assumptions.

I reread each participant's transcript again, in the order that the interviews were conducted and began ascribing codes (nodes in NVivo) to the data. After coding the three interviews from

Family 1 and the interview from Family 2, I printed off a node list (Appendix 35) to check that I had grouped the nodes logically and to have a copy at my side whilst continuing to code across the entire dataset. The files column in this node list presents the number of participants whose data has contributed to that node, and the references column refers to the number of references in total that have been coded under that node. This was a useful way to ensure that I did not omit or duplicate codes. The node list was also a useful document to send to my supervisory team with the annotated transcripts to enable discussions about my progress with analysis. A record of each node list was kept after coding each participant's data to demonstrate how each code evolved or grew. These records are not included here for anonymity reasons. Appendix 36 shows the node list after the data from the first 11 participants (from 5 families) had been coded. Any codes in bold are those which were added from participant 5 to 11's data (from families 3-5). Appendix 37 shows the node list, with new codes in bold, after the data from the remaining six participants from families 6-10 had been coded. Node lists for individual participants are not included for anonymity reasons.

When coding across the dataset I ensured that each participant's data was accurately represented by the sub-code I had previously assigned. A new sub-code was assigned when this was not the case. Transcripts coded before new sub-codes were identified were revisited to ensure that codes were still representative of the data coded under them. This was a time-consuming task, especially given that the level of critical thinking required increased as I progressed with analysis and that layers of interpretation grew deeper. I then started to build node hierarchies (QSR International, 2016). Each participant's data was analysed, interpreted and coded individually, in the same order that the interviews were conducted, before comparison across the whole data set.

I decided not to analyse the photographs in detail. As in Epstein et al. (2006) and Israelsson-Skogsberg et al.'s (2018) studies, the photographs were used only as a stimulus to facilitate communication and understanding during the interview, rather than as a methodology. My reasons for not undertaking a detailed analysis of the photographs were primarily pragmatic: not all participants took photographs, those who did valued them in terms of them triggering the conversations, and like Mandleco (2013) had also found, some participants (mothers in the case of this study) realised that important pieces of technology had not been photographed. Also, although I had asked participants to take photographs about their life with medical equipment (technology) at home, my deliberately non-directive approach in how participants should take the photographs that represented their life at home with medical technology (because I wanted partipants to have control over photographing aspects of living with technology that were important to them) may have resulted in the PE method being too

ambiguous for some participants (Papaloukas, Quincey and Williamson, 2017). Most photographs were solely of the technology or equipment rather than being 'contextually complete' (Collier and Collier, 1986: 163). Most showed little of the context or impact of the technology or equipment in each setting (4.3.2). For example, rather than what I had observed during my visits to their home, the photographs did not show the technology obscuring the television or rooms filled from floor to ceiling with boxes of consumables in the rooms of the homes. As reported by other researchers (Pyle, 2013; Leonard and McKnight, 2015; Papaloukas, Quincey and Williamson, 2017; Williamson, 2018), the photographs taken by my participants did not seem to tell the whole story.

However, using participant photographs in conjunction with their interview transcript enabled me to interpret and report the themes and the meaning behind the themes more easily (Caelli et al., 2003) and to accurately represent the participants' experiences (Hardwick and Worsley, 2011; Tran Smith et al., 2015; Bates et al., 2017). However, I acknowledge that all these data and my interpretation of them are subjective (Bryman, 2012; Gibson et al., 2013; Pyle, 2013) and that it is impossible to gain a total insight into another person's world (Papaloukas, Quincey and Williamson, 2017).

3.5.4 Searching for, Reviewing, Defining and Naming Themes, and Writing Up (Stages 4 to 7)

Although stages 1-3 of data analysis were more linear, I found stages 4 to 7 to be recursive and non-linear. I had to move backwards and forwards between these stages to search for, review, define, name and write up interpretive themes. To start the process of searching for and identifying potential themes I read each participant's data under the codes and sub-codes and created a mind map document in Inspiration® 9[18] to collate and logically order the data (see Appendix 38).

Recurring patterns 'and relationships within the data' could be more easily identified (Cooper and Endacott, 2007: 818) by using the tools in NVivo 11 such as word frequency query, tag cloud and text search query, as I could interrogate the results to identify and explore linguistic connectors and interrelationships amongst or between the themes (Bryman, 2012). NVivo (QSR International, 2016) helped me to find richer insights and connections to not only report the themes but to show the meaning behind the themes (Caelli, Ray and Mill, 2003; Braun

[18] Inspiration® 9 is a mind mapping software that is useful for visual mapping to plan and organise ideas.

and Clarke, 2006; Bates et al., 2017). Overarching themes and sub themes were compared and contrasted, and the evidence weighed (Cooper and Endacott, 2007) to work out the scope and focus of each theme and to define and name the final themes and sub themes (Braun and Clarke, 2013). The mind map and the process of reviewing and defining themes enabled me to be more reflective and reflexive about what the data 'might mean individually and in relation to one another' (Thorne 2008: 163) and to interpret the relationships between the themes, the meanings behind them and the implications of them (Percy et al., 2015). The mind map and node lists were useful tools to share in supervision to clarify my developing thinking.

The raw data were revisited several times over stages 4 to 7. This helped me to recheck my interpretation of the participants' data, and to check that the themes and sub-themes accurately represented their stories when new codes (or sub-codes) were added (when later participants' data were analysed) or themes (or sub-themes) were renamed. This was a time-consuming task, and one that reflects how the 'active role' of analysis often goes unrecognised (Braun & Clarke 2006: 80). Although the codes were initially descriptive and reflective of the language used by the children or family members, as I immersed myself in the data and the layers of my interpretation grew, they evolved to become more informative and interpretive themes.

I interrogated the coding under each code and sub-code again at the end of analysis (Stage 6), thus working deductively rather than inductively at this stage, in order to identify data that would answer the three research objectives ('the technologies or equipment that are used by or for the child', 'whether and how the home is changed by the presence of medical technology' and 'how life at home with medical technology is experienced by different members of a family with a child who has complex health care needs').

The first six stages of thematic analysis (Braun and Clarke, 2013) took 13 months to complete, demonstrating how 'the final analysis is the product of deep and prolonged data immersion, thoughtfulness and reflection' (Braun and Clarke, 2019: 591). Writing up a synthesis of 'analytic narrative and data extracts' for the findings chapter (Braun and Clarke, 2020: no pagination), and 'contextualising the analysis in relation to existing literature' (Braun and Clarke, 2020: no pagination) for the discussion chapter took another five months. This was understandable because this seventh stage of analysis allowed me to add another layer of interpretation to the study findings. During the final writing up stage (stage 7), my second level coding shifted and developed further. For example, my first sub-code of 'Adaptations to' under the code of 'Home' (Appendices 35-37) became the second level coding of 'Necessary adaptations to the home', with the sub-codes of 'Walls moved or knocked down for more

space; Tracking and hoist; Wet room' etc. (Appendix 39), which became part of 'Altered spaces and routines', which then became Theme 1: 'Altered Physicality, Feeling and Meaning of Home'. This theme ultimately became 'Home is Altered, and We Lack Control' in the discussion chapter. Taking a rigorous, inductive, reflexive thematic analysis approach to coding and theming the data enhanced the clarity of analysis and the writing up of findings. It aimed to ensure no confusion exists between the codes and themes and that there are neither too many or too few themes, or too many theme levels (Braun and Clarke, 2020: no pagination). Having identified clear themes made it easier to integrate literature that supported or contrasted with the findings of this study (or gaps in the literature) for the discussion chapter.

3.5.5 Summary of the Analysis Section

Although analysing the data was a time-consuming task, the rigorous and iterative seven-stage thematic analysis method (Braun & Clarke 2006) used gave me the flexibility to move back and forth to provide a rich, detailed, meaningful and interpretive account of the data (Braun and Clarke, 2006; Bates et al., 2017) that is trustworthy (Hardwick and Worsley, 2011; Bryman, 2012).

3.6 Conclusion

In this chapter I have provided a strong rationale for my choices of relativist ontology, interpretivist epistemology, generic qualitative methodology, the PE and semi-structured interview methods, and thematic analysis data analysis. I have argued why these choices were a valuable way to generate, interpret, understand and report the subjective experiences of children and their family members about how medical technology impacts upon their home and life at home. The importance of reflective and reflexive practice, and of acting in an ethically responsible manner for protecting the safety, wellbeing, dignity and privacy of the participants have been highlighted. I have been transparent about what I have done and why and have included 'the often-omitted 'how'' (Braun and Clarke, 2006: 78-79) I conducted the data collection and analysis to enhance the reliability and validity of this study. By facilitating a comfortable interview atmosphere and using honed observation and communication skills, the methods selected have supported me to see, hear and understand the participants' subjective human experiences and emotions. The flexible and systematic, yet rigorous data analysis methods have enabled me to provide a rich and meaningful account of the data. This gives me confidence that the findings and discussion sections of this thesis will be perceived to be a trustworthy interpretation of the participants' experiences and perceptions of how medical technology impacts upon the home and life at home.

The following chapter will present the study findings.

Chapter 4: Findings

4.1 Introduction

This chapter presents the demographic details of the participants and their families before moving onto the 'Setting the Scene' section which describes the categories of technology, equipment and consumables that are required by the children and the types of alterations that are made to the homes of the families. This is then followed by a presentation of the three themes that were identified: Theme 1: Altered Physicality, Feeling and Meaning of Home; Theme 2: The Presence of Carers in the Home; and Theme 3: Home is not Home without their Child.

4.2 Demographic Details

A total of 17 participants from 10 families living across the United Kingdom took part in this study and their details are included in Table 4.1. These 17 participants comprised of two young people who used technology (one female and one male), ten mothers, two fathers, two siblings (sisters from two families), and one grandmother.

The ten families who took part in this study represented 12 children (9 boys and 3 girls) aged 5-25 years, who rely upon technology; two families had two children who required technology (a boy and a girl in both families). The children in three families had been adopted (the child from one family was adopted at age four years and the children from other two families were adopted before the age of two years). Their parents knew at the point of adoption that their child had disabilities, but not the extent of these. The children from nine families had siblings living at home with them (6 brothers and 3 sisters). Six of these nine families had gone on to have or adopt another child after having a child who was dependent upon technology.

Twelve participants took part in auto-driven photo-elicitation interviews, taking solicited photographs, that is, photographs taken especially for the purpose of this study. Seven of these twelve interviews (including the interviews with one technology-dependent young person and the younger sibling) were face-to-face photo-elicitation interviews and five (including the interview with the older sibling) were telephone photo-elicitation interviews due to participant preference and for pragmatic researcher-related reasons related to distance, time and cost. All 12 participants used their own or their parents device(s) (their mobile phone, iPad or tablet) and then shared their photographs with me via email prior to their interviews (parents shared their child's photographs with me via email prior to their interviews). Photographs for the face-to-face photo-elicitation interviews were printed for use in the interview, whereas photographs for telephone photo-elicitation interviews were copied into a

Word document, 6 photographs to a page. This Word document was emailed back to the participant ready for their use during their telephone interview, so that they could tell me which photograph they were referring to during their interview. One participant sent eight photographs prior to their interview but shared a further 21 photographs of forgotten technology or adaptations via email during their interview.

Four participants (including the interview with one technology-dependent young person) took part in face-to-face semi-structured interviews and one participant took part in a semi-structured telephone interview. Three of these participants shared photographs with me via email after their interview.

Interviews varied in length from seven minutes to two hours 38 minutes. Photo-elicitation interviews were longer than semi-structured interviews, and whilst there is some evidence that people can prefer face-to-face interviews to telephone interviews (Groves, 1979), telephone photo-elicitation interviews were longer than face-to-face photo-elicitation interviews, aligning with Cannell, Groves and Miller (1981) evidence that people report more about their health during telephone interviews than they would during face-to-face interviews. The interviews with the two young people who rely upon technology were 33 and 48 minutes long. One young person used an Augmentative and Alternative Communication device to communicate with me during their interview and required extra time to be able to type their answers out on their 'talker'. I maintained awareness that the young people's health care needs and communication challenges would make their engagement tiring for them and was not expecting their interviews to last as long as they did, but the interview lengths were at their choosing. Sibling interviews were seven and 64 minutes long. The shorter interview was with a sister in the 5-10-year-old age bracket, and the longer interview was with a sister from another family who was in the 21-25-year-old age bracket. Eight out of ten mothers' interviews exceeded an hour, and four of these interviews exceeded two hours.

Eight out of the ten families were what sociologists and anthropologists would call 'nuclear' families (Giddens, 2006: 207), that is a family group which comprised of a mother, a father and one or more of their own biological or adopted children. The other two families were single parent families comprising of a mother and two children in each family. Two out of the ten families had moved to their present home after their child was born (knowing that their child required medical technology). This move was not specifically related to their child's needs, although one family mentioned appreciating the additional space in their new home. All ten families owned, rather than rented their home and had lived in their homes, which were (at

least) two-storey dwellings, for around a decade. The families lived in England, Scotland and Wales.

All participants in this study (Table 4.1) had pseudonyms assigned alphabetically (A-J), in the order of participation, except for two children who chose their own pseudonym (Ruby, Sibling in Family 1 and 'Monkey', Child in Family 3). As another means to reduce the risk of breaching anonymity, age range brackets of 5-10 years, 11-15 years, 16-20 years, and 21-25 years were assigned for all children and siblings. The age range of children and siblings who participated in this study were at the lower end of the 5-10-year-old age bracket and the upper end of the 21-25-year-old age bracket. Furthermore, participant identifiers are not linked to the photographs (4.3.2) and quotations in the photograph captions might be from a different family to the one who shared the photograph.

Table 4.1 Participants

Family No.	Pseudonym, Gender & Age Range of Child or Young Person	Types of Medical Technology Relied Upon*	Pseudonym of Person Interviewed (listed in order of participation) Relationship to Child Type of Interview No. of Photographs	No of Residents in Household Family Members Living at Home & Age Range of Child or Young Person's Sibling(s)
Family 1	**Aiden** Male aged 11-15 years	• Medicines • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Communication • Play & Leisure • Consumables	**Amelia,** Mother, Face-face PE Interview, 8 photographs **Ruby (participant's chosen name),** Younger Sister, Face-face PE Interview using Mother's photographs. **Ava**, Non-Resident Grandmother, Face-face SS Interview	3 Mother, **Male aged 11-15 years,** Younger Sister aged 5-10 years
Family 2	**Ben** Male aged 11-15 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Mobilisation & Standing • Consumables	**Bonnie,** Mother, Face-face SS Interview followed by directing the taking of 8 photographs	4 Mother, Father, Older Brother aged 16-20 years, **Male aged 11-15 years**
Family 3	**'Monkey' (participant's chosen name)** Female aged 21-25 years	• Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Mobilisation & Standing • Communication • Play & Leisure • Consumables	**'Monkey', 'Index' Young Person,** Face-face PE Interview, using some of the 19 photographs she directed the taking of sent to me by her mother **Celia,** Mother, Face-face PE Interview, 19 photographs **Colin,** Father, Face-face PE Interview using some of the 19 photographs and then directing the taking of 2 further photographs	3 Mother, Father, **Female aged 21-25 years**, Younger Brother Partly-Resident aged 16-20 years Moved to current home when child was age 17 years.
Family 4	**Deanna** Female aged 16-20 years **Daniel** Male aged 16-20 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Mobilisation & Standing • Communication • Consumables	**Daisy,** Older Sister Non-Resident, aged 21-25 years, Telephone PE Interview, 21 photographs **David,** Father, Face-face PE Interview, using 21 photographs taken by wife and daughter but had compiled list of equipment with wife prior to interview **Deborah,** Mother, Face-face PE Interview, 21 photographs	4 Mother, Father, 2 x children with CHCN: **Female aged 16-20 years,** **Male aged 16-20 years**

Family 5	**Ethan** Male aged 5-10 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Communication • Play & Leisure • Consumables	**Emma,** Mother, Telephone PE Interview, 12 photographs	4 Mother, Father, Older Brother aged 5-10 years, **Male aged 5-10 years**
Family 6	**Finley** Male aged 11-15 years **Fern** Female aged 5-10 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Play & Leisure • Consumables	**Faith,** Mother, Telephone PE Interview, 8 photographs	4 Mother, Father, 2 x children with CHCN: **Male aged 11-15 years,** **Female aged 5-10 years**
Family 7	**George** Male aged 5-10 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Play & Leisure • Consumables	**Grace,** Mother, Telephone PE Interview, 9 photographs	4 Mother, Father, **Male aged 5-10 years,** Younger Brother aged 5-10 years
Family 8	**Hayden** Male aged 5-10 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Communication • Play & Leisure • Consumables	**Hannah,** Mother, Telephone PE Interview, 29 photographs (8 sent initially)	3 Mother, Father, **Male aged 5-10 years**

Family 9	**Isaac** Male aged 16-20 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Consumables	**Isla,** Mother, Telephone SS Interview	3 Mother, **Male aged 16-20 years**, Younger Brother aged 11-15 years Moved to current home when child was aged 6 years
Family 10	**Jacob** Male aged 11-15 years	• Respiratory • Medicines & Health • Eating & Drinking • Toileting & Bathing • Sleeping • Seating • Mobilisation & Standing • Communication • Play & Leisure • Consumables	**Jenna,** Mother, Face-face SS Interview followed by her child directing the taking of 10 photographs **Jacob, 'Index' Young Person,** Face-face SS Interview, followed by directing the taking of 10 photographs and pressing to take the photograph	4 Mother, Father, Older Brother aged 16-20 years, **Boy aged 11-15 years**

4.3 Setting the Scene

This section of the chapter will present an overview of the 10 categories of technology, equipment and consumables that were reported as required by the children. The types of alterations that were made to the homes of the families to be able to care for their child at home will also be described. A picture gallery of some of the photographs of the technology and equipment and positioning of furniture in the home is presented.

4.3.1 Types of technology

The children and families required between seven and 10 categories of technology or equipment to prevent their death or further disability and/or to sustain their health and wellbeing. In total, 137 items of technology, equipment and consumables were identified as being used by the children and families; these are presented within ten categories listed in Table 4.2.

Although I categorised the technology and equipment into 13 major categories for the integrative literature review (Table 2.4), I categorised them into 10 major categories for the findings of this study (Table 4.2). This was because ‘Car or Van Modifications’ were categorised under ‘Mobilisation and Standing’ for this study. The specialist exercise machine was categorised under ‘Play and Leisure’ for this study, rather than under ‘Specialist Therapies and Equipment’, because the child perceived it to be a fun way of obtaining exercise. Finally, with the exception of a sharps box, which was categorised under ‘Consumables’ for this study, participants did not discuss ‘Safety Equipment’, such as safety gates and fireguards, that were discussed by participants in Nicholl et al.'s (2013) study.

Some children required technology continuously for 24-hours a day, and other technology was only required for part of the time, typically whilst the child was asleep. The Picture Gallery in Section 4.3.2 contains photographs of some of the technology, and some context for each of these. There was a wide variety of technology in terms of purpose and size. Some types of technology were evident within many of the homes whereas other pieces of technology were less typical. Some items of technology are very large and heavy, for example, the oxygen concentrator shown on the floor to the left of the storage unit in Image 4.1 and power chair (electric wheelchair) shown in Image 4.2. Other items, although small, were required in large quantities. All this technology comes into the home from external sources. Some of this arrives on a regular basis, for example, some families take delivery of 350 nappies every eight weeks and 30 bottles of the night-time feeds every four weeks for each child.

Table 4.2 Technology, Equipment & Consumables Required by the Children

Category of Technology & Equipment	Examples of Technology, Equipment and Consumables Given by Participants
Respiratory (Breathing) (n=42 items) Required by the children in 8 families	Long term mechanical ventilators; Continuous Positive Airway Pressure (CPAP)/ Bilevel Positive Airway Pressure (Bi-PAP); Oxygen cylinders; Oxygen concentrators; Nebulisers; Suction machine with pot, filter & tubing attached; Ambubag, which contains a self-inflating resuscitation pump; Oxygen saturation monitor's (SAT's machine); Pulse oximeters; Nasal Pillows; Humidifiers; Suction Sample Catchers; Nebuliser set with oxygen T piece; Oxygen tubing with oxygen connector for nebuliser set; Heat & moisture exchangers for tracheostomy humidification; Oxygen connectors; Oxygen saturation probes; Medical tape; Suction catheters; Tracheostomy cleaning sticks; Cannula cleaning powder; Velcro tracheostomy holders; Wipe wash cloths; Charging units; Tracheostomy tube; Suction attachment; Oxygen bubble tubing; Oxygen tubing with double connector; Tracheostomy; Replacement suction pot & filter for suction machine; Suction tubing for suction machine; Medical gloves; Alcohol hand gel pump; Bandage scissors (small & large); Lubricant gel; Tracheostomy Wedge; Barrier cream; Tracheostomy ties; Sleek tape; Saline wipes.
Medicines, Medical & Health (n=4 items) Required by the children in all 10 families	Nasal, oral &/or rectal prescription medication; Vagal nerve stimulator; Syringe driver; 'Line Support'.
Eating & Drinking (n=27 items) Required by the children in all 10 families	Feeding pump; Feeding pump stand (tall or small); Feeding pump electrical charger; Giving sets; Feeding bottles; Feeding containers; Gastrostomy pegs; Gastrostomy MIC-KEY button kit; Introducer for button; Gastrostomy drainage bag; Enteral syringes in various sizes to administer medications; Caps for enteral syringes; Slip syringes for gastrostomy button maintenance; Extension set Y port enteral medication attachment for gastrostomy; Extension set right-angle feeding attachment for gastrostomy; Straw to administer medication; Bottles of sterilised water for gastrostomy balloon; Mobile feeding sets with Y port; Bolus feeding set; Fibre liquid feed, bottles & packs; Wound dressings; Cloth pads for gastrostomy; Protective clothing; Towels & Muslins; Special cups & bottles; Non-slip mats; Specialist chair with a tray.
Personal Care (n=11 items) Required by the children in 9 families	Specialist Baths; Shower Trolleys; Shower Chairs; Bath Seat; Bath Step Stool; Enteral & bladder catheterization; Toilet Seat; Nappies & pads (all children & young people were aged over 5 years); Nappy sacks; Baby wipes; Creams such as Sudocrem & Metanium.

Sleeping (n=10 items) Required by the children in all 10 families	Sleep System; Webcams, video & audio baby monitors (even when the child is older); Child's own communication device to text/email from; Monitoring devices such as an apnoea & oxygen saturation monitor (included in the respiratory section above); Continuous Positive Airway Pressure (CPAP)/ Bilevel Positive Airway Pressure (Bi-PAP) machines (included in the respiratory section above).
Seating (n=5 items) Required by the children in 7 families	Home Chair; Pea Pod; Wheelable Special Chair with Tray; Floor Sitter; Activity Chair.
Mobilisation & Standing (n=18 items) Required by the children in all 10 families	Manual wheelchairs; Electric wheelchairs (also known as power chairs); Some families had both manual & electric wheelchairs; Moulded seats; Tracking & hoists; Through floor lifts; Ramps into home & vehicle; Motability van modified to include manual or electric ramps or tail lifts. Other equipment included: Head controls; Wheelchair canopy; Wheelchair tray; Harnesses & straps (including foot & groin straps); Standing frame; Walker; Positioning equipment, supportive brace or cast, splints & orthotics; Special shoes or boots; Allen key for wheelchair adjustments.
Communication (n=5 items) Required by the children in 6 families	Augmentative & alternative communication devices (AAC) such as eye gaze computers; iPad to communicate/see/hear immediate &/or extended family or friends via social media or email; Stopwatch app on phone to support feeding & medication; Doorbell or telephone as an intercom for carers to alert parents of an emergency.
Play & Leisure (n=5 items) Required by the children in 6 families	Adapted trike; Indoor Bike; Specialist Exercise Machine; iPad's used for play; Sensory Play Room.
Consumables (n=10 items) Required by the children in all 10 families	Batteries; Gloves; Hand Gel; Dressings & Tapes; Extra Bedding; Syringes; Sharps Box; Furniture such as a wheeled trolley to store life-saving medication on; Saline & special water.

4.3.2 Picture gallery

Image 4.1
'*Big … massive … hip height … not portable and weighs a tonne*' oxygen concentrator on the floor to the left of one organised storage unit.

Image 4.2
'Massive' 'cumbersome' power chair that can be *'a metre long and two foot wide'* and weigh over *'100 kilogrammes'*.

Image 4.3
'Our house looks like a hospital, rather than a home ... because we've got the ceiling track hoists' that are intrusive and unsightly.

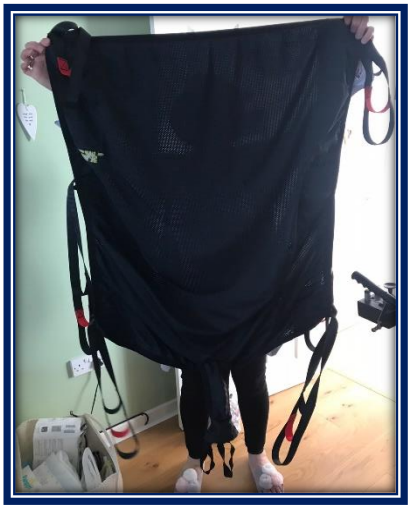


Image 4.4
Child is *'not keen on the' sling'* that attaches to the hoist – feels *'too hot'*.

Image 4.5
'Weird hole above' doors for tracking and passage of hoist and child in sling.

Image 4.6
'Safe sides' bed – *'the type of bed that would keep him safe… [so that] I can go to sleep'*.

Image 4.7
'Hospital bed' with metal sides and headboard.

Image 4.8
'Cumbersome' 'Bespoke height adjustable bed'.

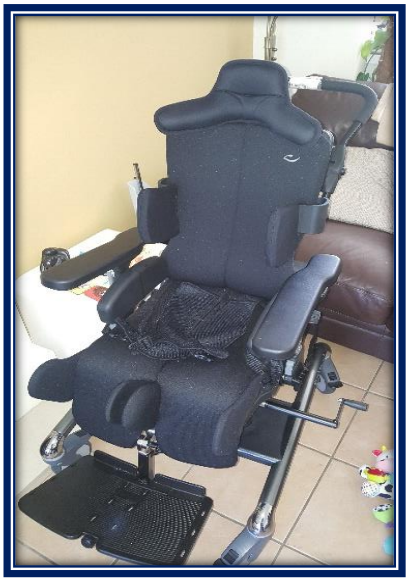


Image 4.9
Home chair in front of the sofa. Dwarfs the lounge. *'I always move, because I can't see the tele, so I always have to move it'. 'It takes up all the room'.*

Image 4.10
'Really cumbersome', 'uncomfortable' shower chair.

Image 4.11
Shower trolley – need a *'bigger one'* now that their child has grown.

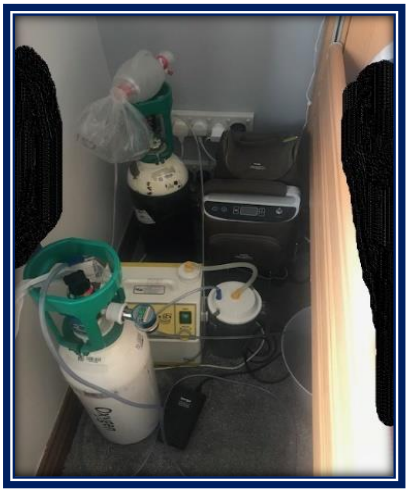


Image 4.12
Parents must find *'a spare bit of floor'* underneath or at the side of the bed for their child's technology and equipment.

Image 4.13
Wheelchair frames and walkers are stored in the bathroom *'because that's the only place'* they fit.

Image 4.14
'Like a Storage Facility'. An example of only some of the consumables (not nappies or technology).

Image 4.15
Augmentative and alternative communication system with eye pointer that children become *'depressed'* without as they are not included in conversations.

Image 4.16
Specialist trike with oxygen cylinder on back.

Image 4.17
Sofas are pushed into alcoves and against walls so that child (seated in wheelchair at bottom of photograph) can mobilise into room.

4.3.3 Types of Alterations that are made to the Homes of the Families

Alterations to the physical structure of the home and changes to how the rooms are used in the home were necessary for families to have a space with adequate facilities and access to meet their child's medical needs. The extensions and adaptations that were made to the interior and exterior physical structure of the homes and the alterations to how the spaces within the homes were used are described in this section. These alterations had an impact on the families, which are described later in this chapter (4.4, Theme 1).

Five families (Amelia; Celia and Colin; David and Deborah; Emma; Jenna) had their home extended to build a downstairs bedroom, wet room or space for their child. Only two families (Amelia; Emma) had their extension fully funded through a local authority Disabled Facilities Grant. One family (Jenna) partially funded their extension, whilst two families (Celia and Colin; David and Deborah) fully self-funded their extension.

All ten families mentioned having at least two adaptations made to their home. Nine families removed or moved walls or reconfigured how the rooms were used in their home, for example, converting their garages, kitchens or lounges into an appropriate bedroom, wet room or space in which their child could be cared for and could mobilise within, or so that their child could take part in family activities within their home. The bedrooms for the technology-dependent children were situated downstairs for seven families. Some families had altered the use and function of rooms several times, for example, first converting the garage into their child's bedroom and then later moving their child's bedroom to the lounge. Two families had opened up virtually the whole of the ground floor of their home for their child, whilst four families emphasised the importance of having their kitchen extended or knocked through into another room to create enough space to be in close proximity to their child, so that they could always see and hear them and be vigilant to their needs.

Nine families had a special bathroom or wet room installed for their child. This was fully funded by a local authority Disabled Facilities Grant for eight families. Emma and Hannah both had a special bath for their child, whilst other families had to have their bath removed (even though they had other young children who preferred a bath). Three families had doorways widened. All the homes apart from Grace's had at least one hoist and ceiling tracking fixed to the ceilings; this often involved the workforce having to access the upstairs floors of the home to reinforce the ceilings to bear the weight of their child and their equipment. Two families had lifts installed, which involved creating a large hole in the floor of the room above for the lift to pass through. Seven families talked about receiving funding from NHS Continuing Care for

installation of extra electrical sockets, because of needing to use several different types of technology for their child at the same time.

Adaptations to the outside of the house were also required. Eight families had a concrete ramp or graduated path installed to create access into and out of the house because their child and their wheelchair were too heavy to lift or tip back over the original step(s). The remaining two families did not require a ramp as the doorway into their home was level with their drive and did not have any steps. Four families had levelled or sloped their back garden themselves so that their child could access that space and take part in family activities. Other families mentioned having to go to the expense of obtaining paving or tarmac in their front garden to park their van on and mobilise their child across.

Four families had the *adaptations* to their home fully funded through a local authority Disabled Facilities Grant (in contrast to the *extensions* that were funded by a Disabled Facilities Grant). Two families self-funded their adaptations. Four families had their adaptations partially funded (the local authority funded their child's wet room). One of these four families required an extension before their child was three years old (which is the Disabled Facilities Grant eligibility age), so they funded the adaptation to alter their garage into a downstairs bedroom themselves and then once their child was old enough to meet the eligibility criteria, they then had their extension and adaptations fully funded by their local authority. Another of these four families self-funded some of their child's mobilisation technology (tracking and hoists).

In the following sections the three themes which developed from the analysis and which relate to the impact of the children's need for technology upon the home and life at home will be presented. The three themes identified from the data are:

- Theme 1: Altered Physicality, Feeling and Meaning of Home. This is the largest theme which is about the impact of the alterations to the physical structure of the home, how the rooms in the home were used, and the presence of technology, equipment and consumables for the look, sounds, feeling and meaning of home.
- Theme 2: The Presence of Carers in the Home. This theme concerns the impact upon family privacy and the feeling and meaning of home. The home becoming a place where paid carers support the care of their child.
- Theme 3: Home is not Home without their Child. This theme is about how the technology, equipment and consumables prevent unnecessary hospitalisation and enable their child to live at home with their family as part of a community.

4.4 Theme 1: Altered Physicality, Feeling and Meaning of Home

The focus of this theme is on the impact that the altered physicality of the home has upon the feeling and meaning of home. This theme starts by focusing on the impact of the extensions, adaptations, repurposing of rooms and the altered décor and furnishings on the look, feeling and meaning of home. The focus then shifts to considering the impact of the technology, equipment and consumables for the look, sound, feeling and meaning of home. The final section focuses on the control (of lack thereof) that parents felt that they had in relation to the adaptations that were made to their home. It also addresses how their involvement in decision making enhanced their feelings of control and led to acceptance of the adaptations, allowing them to feel more at home in their home.

4.4.1 A home with an altered physicality

The families all wanted to be able to care for their child at home and although the extensions, adaptations and alterations to the physical structure of the home were necessary, these changes altered the feeling and meaning of home.

Parents reported that caring for their child at home had a negative impact upon the physical, emotional, psychological, social and financial health and wellbeing of all the family members. However, despite these negative impacts for the family members' health and wellbeing, parents accepted that their child's needs had to be prioritised for their child to be able to live at home and be part of the family. The importance of her home being a *'nice, safe environment'* meant that Deborah had to prioritise how her children who rely upon the technology would access and use the spaces in their home over the needs of the other family members, including their *'eldest daughter who didn't have any medical needs'*:

> *Each room has had to first be thought about as to how it meets Deanna and Daniel's needs, to ensure that they can use that room… it's got to work for Deanna and Daniel first (Deborah).*

Some parents were particularly resistant to intrusive and unsightly adaptations that significantly altered the look of their home; ramps and ceiling tracking and hoists were particularly disliked. Some families had no choice but to have a ramp installed to get into the house, because they (and carers) cannot carry, or tip their child and the wheelchair up any steps. This was because the wheelchairs are *'ridiculously heavy'* (Daisy, sister), weighing *'over 100 kilogrammes'* (Celia), not including the children's weight (Image 4.2). Celia said that her daughter could not even go to see their new house until the ramp was installed just before

they moved in *'because it had a step at the back [and the front]'.* She noted *'you still can't get in at the front door. [Daughter] comes in round at the back'*.

Although three families had a concrete ramp or graduated path at the front of their home, other families resisted this and preferred having a ramp at the back of their house even though this meant having to navigate a side gate and having security concerns, such as the rigmarole of having to lock side or back gates to take their child in and out of the house. Celia said that '*somebody's got to go from the back door and close the side gate. And lock it after [Daughter's] gone through… you've got to make sure that gate's locked or bolted'*. Amelia said that she had become '*lax with locking'* the gates because of the effort required with getting the keys and that as a result of this she '*had people [intruders] in the back one time'.*

Five families did not have hoists in shared family areas, such as lounges. Amelia said that this was because of the visual impact upon the home. Images 4.3 to 4.5 clearly reveal the visual impact and perceived imposition of tracking, hoists and slings on the look of rooms. Amelia explained, '*I wanted the house to be sort of normal… I didn't want tracks running all the way through my house really'.* Emma talked of the impact of this sort of equipment in shared family areas where rest and relaxation would typically occur:

> *I do find it really difficult because our house… looks like a hospital, rather than a home, especially in the living room because we've got the ceiling track hoists going right the way through the [downstairs of the house]* (Emma).

Some types of tracking and hoists are particularly invasive, requiring a hole to be cut out of the top of doors and door frames for the hoist to pass through (Image 4.5). Celia said how this type of adaptation *'alters your home'.* Emma corroborated that having *'a weird hole above [her] … doors'* impacted upon the aesthetics of her home.

Some people had strong memories of the through-the-ceiling lift being installed and they talked of the impact this had. The lift in Faith's home '*goes up into… [Faith's] bedroom'* so she cannot avoid the look of the adaptations and technology even when she goes to bed. Daisy (Deanna and Daniel's sister) distinctly remembers the installation of the lift, despite being very young at the time, because the space for the lift *'was just a massive hole in the floor'* of her bedroom.

Spaces in the home such as garages and lounges had to either be given over completely or shared to create safe areas where their child could be cared for. However, such changes even when done for the right reasons often felt strange or wrong as it disrupted usual family living

arrangements. Having their child's bedroom downstairs and away from the rest of the family did not feel normal for some families and caused distress. Bonnie was still distressed a decade after her son's bedroom had been moved downstairs, revealing that the changes to how the home is constructed can be profound and long-term for the family:

> *We don't live as a family really, the way your typical family would live. I found that hard at first… There was just no question that I would not be down here with Ben [Ben requires 24-hour care]… Then sometimes [husband] will say "I'm going to sleep with you two tonight" and then he'll come down. But then I think that [Ben's brother] is upstairs on his own. What if there's a fire, what if…? I think you think things like that, because ordinarily you would never leave your children sleeping downstairs in a house, would you? (Bonnie).*

Parents felt like their homes and the functioning of their family were worlds apart from those of families who do not have a child who is dependent upon technology. Emma explained that Ethan sleeping downstairs *'sort of just happened really. It is odd'.* Jenna talked of her feelings about her son sleeping downstairs, noting that she *'felt a bit awful for him [Jacob], because he was stuck down here on his own'.* Deborah talked of the normality of her children's bedrooms being upstairs:

> *I feel like it [having the children's bedrooms upstairs] brings that bit of… I am not saying that we are striving to be normal, we're not, but your life can't just become about the disability, you have still got to function as a normal family. That has always been sort of our philosophy really, as normal as possible, as far as we are able to, we try and do normal things and it is normal for a family to go upstairs (Deborah).*

The function and look of other rooms were often altered; the lounge or dining room and bedrooms had to change to create appropriate bedrooms or spaces where their child's medical needs could be met. Jenna talked of how Jacob's bedroom had been situated in three rooms:

> *When [Jacob] was younger he had one [a bedroom] upstairs… This [back room] used to be the lounge and the lounge [front room] was his bedroom… because it wasn't as far to walk [from our bedroom]… to help him in the night. But we got new neighbours - they are not noisy, but… are a bit noisier… and they were keeping you awake a bit, so we swapped rooms back, didn't we, and you came in here [back lounge]? [talking to Jacob] (Jenna).*

Adaptations, changes in usage and prioritisation of the needs of the technology-dependent children over other family members altered the look of the shared family spaces in the home. These were constant reminders that their home had a medical purpose, and some felt that their home was not so much a family home as their child's home. Isla explained that the look and shape of her adapted bathroom was a constant reminder that her home is primarily focused around her child's needs and not her own needs or those of her other son:

> *[My house] is all set up for Isaac, really. Like, my sitting room has got a lift in it… and… we haven't got a normal bathroom, it's a disabled bathroom that me and [child's brother] use, but it is, it's Isaac's bathroom, it's not our bathroom, it's his bathroom. There is no bath, which is not a good thing for [child's brother]… I had to lose it because we needed Isaac with a shower... I am conscious every time that I go in it that it is a disabled bathroom… it is, it's a bathroom that is set around Isaac's needs and it's a very long bathroom because it was two rooms knocked into one, so it's an odd shaped bathroom, that you know, it doesn't look like a bathroom, either (Isla).*

It was evident that families wanted their child '*to access the whole house as much as possible*' (Deborah) and to be included in family routines and activities. Six parents emphasised the importance of having space in the kitchen so that their child can access that room. However, although open plan living is contemporary and often seen as something to aspire to, some families had no choice but to create open plan spaces where their child's technology was integrated with the everyday objects of family life. Isla had their kitchen and sitting room knocked into one room and found this supported family functioning. However, Hannah and Emma, who had opened up the whole downstairs of their homes, had conflicting emotions and remained somewhat unhappy about how these changes had made their home look like a hospital but accepted that they needed these to be able to care for their child at home. Although Grace and Daisy (sister) said that they stopped noticing the technology and equipment in their home over time, it was evident that some mothers were still deeply affected by the medicalisation of their homes even after several years. Emma compared her home to the homes of her friends and said that she will never get used to her home looking like a hospital, despite now being able to care for her child at home:

> *Our house, to me, our house looks… I don't think I'll ever get used to it, actually, to be honest [laughs]… I think the thing that is really difficult is that it looks really strange downstairs… cos everything is like a hospital… It's hard, because half of me wants my house to look like a house, but the other half of me wants to be able to help him, so you just deal with it then because of him needing it, but*

> *it is difficult… I find it really difficult. I'm always saying to my friends 'Oh, our house looks like a hospital!' … I'm aware if I go to my friend's house, their house looks cosy, like a home. To me, our house looks quite clinical, you know? (Emma).*

Amelia talked of having a home that *'revolves'* around her son, with the extensions and adaptations being *'purpose built'* for him. Celia spoke of how her house was *'entirely'* designed for her daughter and Isla said that her home was '*all set up'* for her son's equipment. The result was that their homes neither looked like nor felt like home. This sense of their home not looking or feeling like a home was expressed by most parents. Hannah powerfully expressed this sense of feeling out of place at home because of the changes to the physical structure and look of her home, *'We have made such significant changes to our house… we feel out of place in our own house sometimes... It's not our house anymore, it's Hayden's!'*

Faith was concerned about whether the look of the adaptations might impede their ability to sell their home, saying, *'[the technology], it sort of holds you [and prevents you from moving to a new house]… because who wants a house with a lift in it, you know?'* She suggested that potential purchasers would not be able to see past the technology and permanent disfigurement caused by cutting large holes in ceilings for the lift or having *'hoists screwed to… [the] ceiling'.* Although all the families owned their own homes, Faith was concerned about how *'spoiling the cosmetics'* might prevent landlords from agreeing to the adaptations that families who rent their home might need.

Several parents talked of how the technology and equipment take their toll on both the décor of the home and their choice of décor. Colin said how *'you can't keep a pristine house [because]… even with [widened] doors and so forth, you still get knocks on doors'*. David said that they *'have decorated the house lots and lots of times'* because of the constant knocks and damage to '*the sides of the walls, [and the] doors'.* Ava (grandmother) and Faith spoke about larger types of technology, such as the power chair and walker, being kept at school because of the damage that they cause to the décor and furnishings of the home. Faith explained:

> *Finlay has a power chair [that he uses at school and when he goes to the hospice]. He has got a power chair, but he doesn't have it at home – he's too dangerous with it [laughs]. He smashes into the walls and we wouldn't have any furniture left (Faith).*

The rooms accessed by the child in the homes of most families were painted white, cream or beige so that they could be touched up easily when knocked by the wheelchair, bed or other technology or equipment. Colin said that he was grateful for the architect's advice about decorating:

> *We were thinking of wallpapering, but the architect quite correctly said, 'Well, just do them [the walls] a fairly neutral colour' and in a way, that has been a fairly good thing because at least it means that when it gets messed up, I can just sort of touch it up (Colin).*

Some families mentioned how they were not able to have the embellishments that would help make their house to feel like a home because of hygiene or health and safety reasons. Most of the families had wooden, laminate or tiled flooring even though some would have preferred carpets. The families who had kept some carpets, say in their child's bedroom, either for sound insulation or for their child to lie on, regretted this due to the wear and tear and dirt caused by the wheelchair, constant footfall of carers or spillages on the floor. Some families had to remove furnishings such as rugs as they were unable to push their child's wheelchair or seating equipment over them. Other families had to add furnishings that they would not have ordinarily chosen, such as a runner across the length of rooms to try and protect their carpet from wear and tear from their child's wheelchair.

4.4.2 Altered 'home for all of us': Experiences of having extensions and adaptations

All parents expressed extreme gratitude for the extensions and adaptations to their home. However, families whose extensions and adaptations were funded or partially funded by a local authority Disabled Facilities Grant and whose workforce were employed by the local authority had worse experiences and felt more out of place in their home than those who self-funded them. Their negative experiences and memories were due to the lack of control that they had over the alterations to their home, with Deborah stating that home should be *'our place… the place where I am in control.'*

Nearly all the mothers felt like their local authority took a utilitarian approach and prioritised the cost of the extension and adaptations over the needs of their family members and family life. Deborah explained that her local authority had *'complete disregard for [her house] as a home'*. She said:

[They were like], 'Where is going to be the… quickest… cheapest place to put it [the lift], with the minimal amount of cost… [and] the least amount of work for them… Don't care that that is then going to disrupt your whole house (Deborah).

This was the reason why Deborah's family withdrew from the Disabled Facilities Grant application process and raised the funds for the extensions, adaptations and technology themselves. Isla corroborated that *'it is all to do with finances'* explaining that she felt like her local authority were *'waiting for him [Isaac] to die, rather than putting… [their] hands into… [their] pocket.'* She recalled that when her local authority realised that '*we are going to have to deal with it',* their attitude was *'what's the cheapest way that we can deal with it?'* Faith also spoke about the difficulties in acquiring the adaptations to her home being '*a challenge all the time, it's always been… it's all to do with money, money, money, money!'* Being able to raise the money for the adaptations themselves made the difference between the space in their home being used in a way that suited the family or not. Deborah said that their adaptations would not have worked well for the functioning of their family had they not funded the extension and adaptations themselves. She said that her children's bedrooms would have been downstairs, and she would have been uncomfortable with this:

Because they [Deanna and Daniel] are both severe epileptics and it is bad enough going to sleep when they are right by you… If we had been getting the grant, they [the council] wouldn't have costed the lift in, they wouldn't have paid, they would have just said 'No! The children will just have to sleep downstairs! (Deborah).

The families who had their extensions and adaptations fully or partly funded by a Disabled Facilities Grant did not feel involved or listened to during the application, planning and building processes. They did not know that they could '*have an input… [or] say 'No' to things'* (Bonnie). The memory of money being prioritised over family life and not having any control impacted upon how these parents felt about their home when they looked at the adaptations and the rooms in their home. Bonnie discussed how those employed to oversee the adaptations seemed to forget that her house had been their family home for a long time and, as such, the family members knew how the spaces would work best for them. The '*dictatorial'* approach in which Bonnie was just '*told'* how the adaptations would be made to her home had a lasting impact upon her hopes, dreams and expectations of home:

The people that do the plans, like all the architects… they're the ones that… control the purse strings and they did it all, so we sort of stepped back… Agency services are very… they don't really have input with families as such... They are

like architects and… because they've seen something on a piece of paper, and they've seen legislation… they think that they know more than you. And I know that sometimes you can't have what you want because it's not going to work… [but] it's my house and I feel like I have been dictated to as to what I can and can't have. I said, you know, we worked hard to buy this house and I feel like it was taken away from me (Bonnie).

Bonnie and Emma were clearly frustrated at their inability to be involved in the adaptation processes. For Emma's family, this had a negative impact for Ethan's mobility in their home and garden, and for his family and carers' physical wellbeing:

When we had the grant for the room, the council architect designed the way that it was going to be – so they planned to have the bed sticking out like it is in the photo [photograph not used to protect anonymity], but it means that you've got hardly any room to freely walk around the edge of the bed to the bathroom… [or through the] patio doors that lead out into the garden. So, in the summer, if we want to take Ethan out into the garden, we have to move the whole bed, just to get him in the garden (Emma).

Three mothers spoke about their negative experiences with the builders who were disrespectful when they carried out the adaptations to their homes. Emma said that *'the problem is with these builders and things, they're completely inconsiderate to whose house they are in!'* She explained that the builders were smoking in the room that was going to be her son's bedroom. Faith said that the builders left '*a right mess'* when they converted her garage into a bedroom for her son and the long-term memories of this '*right nightmare'* were still evident. Bonnie said that *'there was no pride in their [the builder's] work'* and corroborated about poor workmanship which has annoyed her on a daily basis for over 10 years. She said that she has regained control over the space and appearance of her home - '*taking it [the home] back'* and getting '*the layout the way'* she wants by funding it themselves over time.

Those families who had more control over the alterations to their home because they had fully or partially funded them experienced having adaptations that were more aesthetic, practical and functional than they had envisaged, and thus, their home felt like their own. By fully or partly paying for the adaptations themselves, the families could employ architects and builders who either had specialist knowledge of the needs of families like theirs, or who were willing to obtain this knowledge through working in collaboration with the family and health professionals. These architects and builders were '*adaptable… [and took] a real interest in the job because*

they had priced it and didn't need to move onto the next job quickly' (Colin) and had time to have *'a proper think'* about how the extension and adaptations to the home would meet the family's *'long-term needs'* (Deborah). Colin, David and Jenna spoke about receiving individual attention from a very small team of experienced architects, builders and health professionals. The fathers from two families (Colin, David) both stressed the importance of those who were involved in the adaptations understanding '*how a big electric wheelchair, would work in [the home] environment'* (Colin) or how to *'make best use of the space… [to enable them] to function within the home… function as a family… [because] it is still our home'* (David), and *'it had to be home for all of us* (Colin). David said that the combined experience and foresight of the architect and physiotherapist ensured that his home was organised, accessible and functioning and could meet the long-term health and wellbeing needs of the whole family. These factors were clearly important for the families to function as a family and for their home to feel like their own:

> *So, from very early on everything was designed knowing that we needed wider doors, turning circles [the amount of space that is required to turn a wheelchair around in], the need for high sockets… So, we were lucky in that respect… if he [the architect] didn't have the knowledge for wheelchair adaptability, then… [the physiotherapist] could offer advice… so that worked… all those things – little things were thought out (David).*

Colin also spoke about the importance of the architect having an ongoing relationship with the family and in his case, their child's Occupational Therapist, to think of things like *'the tracking going through',* so that the adaptations were functional for the long-term needs of his family. Jenna commented as to how working with the builder made the difference to the positive outcome of their extension and adaptations:

> *The builder looked at the plans and said, 'Oh, this is not going to work!' and just adapted them [the plans] slightly - he was spot-on, absolutely spot-on with what he said (Jenna).*

Families were less able to function in their home when their child's future needs were not considered. Faith and Emma said that by the time they had fought the local authority to fund and install their child's adaptations or technology, they were no longer appropriate for their child's needs. Jenna said that her kitchen '*wasn't safe for him [Jacob], as it was then'* and how *'he wouldn't have even fitted in it now… that he's in a bigger chair'* had they not partially funded the extension and adaptations themselves. Deborah explained that self-funding their

adaptations meant that they were able to protect Daisy's (Deanna and Daniel's sister) privacy needs:

> *[The lift] was going to go up into Daisy's [older sister's] bedroom, and before we extended [the house] Daisy and Deanna were sharing a bedroom and I thought 'Gosh, not only has Daisy got to share a bedroom with Deanna, she's then going to be having this great big lift coming up into her bedroom. Erm, erm, No!' (Deborah).*

The control Deborah had over the lift, hoist and downstairs space in her home meant that, a decade later, the extension and adaptations are *'still doing what… [they] should be doing now… Still, still, still good… because we had really thought about it beforehand... It is amazing!'* (Deborah). Jenna was happy that partially funding their extension and adaptations had met Jacob's and her family's long-term needs thus preventing the need to move to a new house:

> *We said that we wanted a bigger extension and we'll put the money towards it to get what we want, because, we said at the time, 'We don't want to get the adaptation done, and then find out that we have to move in five years because it's not suitable anymore, you know, we want to stay here [in this house]' (Jenna).*

Jenna considered it false economy for the local authority to not ensure that adaptations are future proofed for children's safety, privacy and dignity needs as they grow older:

> *That's what really annoys me about the NHS and people who provide funding for things, because they don't think long-term. It's okay if you are dealing with adults who aren't going to grow or change much, but children, they think of them at the size they are, and they don't think about them growing up and getting bigger equipment… and getting bigger themselves and they just waste money because people end up having adaptations and then growing out of them and either needing to apply for more funding to do a bigger extension or having to move house and start again (Jenna).*

Similarly, Bonnie was clearly frustrated that her family are going to have to go through the upheaval of more adaptations now that Ben is a teenager. She said, '*I don't know why they didn't just do that in the first place, cos it's going to cost them more money now to redo it again and to do it properly.'*

It is evident that the future needs of the children and their families should be considered when adaptations are being made to the home.

4.4.3 A home that looks different

Whilst changes to the physical structure of the house impacted on how the families felt about their homes, the technology, equipment and related consumables within the house also influenced how they perceived their homes. Some technology and equipment are '*obtrusive'* (Deborah), *'clinical'* looking (David and Deborah), and can make the home look *'strange'* (Emma) and *'very hospitaly'* (Grace). Colin said that good technology is that which fades into the background and is not noticeable. Parents wanted to make these things in their homes as '*unobtrusive'* (David, Colin) and *'as unmedical as possible'* (Grace) as this would help them to feel at-ease, *'be comfortable'* (Deborah), and have qualities such as being *'cosy'* and '*relaxed'* that Emma and Deborah said that they require for home to feel like home. Equipment such as special beds and life-saving technology all impacted on the families, as did the need to store equipment and consumables.

Although beds are typically big items of furniture (and thus, not discreet), the specialised beds used by the children had a different aesthetic to typical beds, as can be seen in Images 4.6-4.8. Although some parents said that they liked their child's bed because it was the only place that their child was safe, David spoke about the beds their children were offered a number of years ago, being '*like a box, and… just looked like a coffin'*, demonstrating how powerful the visual impact of the design of the technology within the home is, not only medicalising the home, but also being a constant reminder for the family of the fragility of their child's life.

Colin said that their local authority is only *'interested in… functionality'* rather than how *'attractive'* the technology is when they offer it to families, whereas families typically consider both aesthetics and functionality. Daisy (sister) corroborated what Colin had said by explaining that her brother and sister's beds are *'quite dull… not pretty… [but are] functional'*. Deborah, like most of the parents, specifically referred to her children's beds as being a hospital bed or a profiling bed, rather than just referring to them as a bed. Although Colin spoke about technology such as feeding pumps getting smaller over the past twenty years that they had been living with it, his wife, Celia, spoke specifically about the advances in the aesthetics of specialised beds over the years during her interview, as her daughter's bed now looks like a '*normal bed and it's come with [colour], a proper headboard and nice-looking sides*'. This was not the case for all families as the children's beds in some homes looked clinical because of having metal headboards or sides (Image 4.7). Natural coloured materials such as wood or pale colours but not *'crappy beige, or naff grey'* (Hannah) appeared to help the bed look less

clinical. Grace talked of how her son's bed *'fits in fine with his room and his décor'*. Having a bed that did not *'look too clinical'* (David) and using colourful bedding and furnishings to mitigate the dull colours enabled this type of technology to be integrated into the home more, which enhanced David, Celia and Grace's ability to accept them more.

Although parents like Hannah kept the '*really medical'* life-saving technology, such as '*the ambubag and the foot pump'* (Hannah) to hand in case of emergency, they also tried to hide or conceal these and other pieces of equipment such as oxygen saturation monitors, suction machines and oxygen. These were the types of technology and equipment that parents *'associated with hospital'* and were both a memory of the times that they had resuscitated their child and '*a constant reminder of [their child's fragility of life]'* (Deborah). They were the types of technology and equipment that, at one time, had been those that parents had hoped that they were *'never going to see [at home], because… [they] only use them in an emergency* (Hannah).

Although the amount and *'size [of technology] is definitely a factor [impacting on the home]'* (Colin), some mothers mentioned that they had forgotten about some of their child's technology and equipment. Technology and equipment such as the van (Amelia, Emma, Hannah), supportive chair, ramp, bed, oxygen concentrator (Hannah) and wheelchair (Emma) may have been forgotten because they were outside the house or in another room at the time of their interview or taking the photographs, or because parents did not consider these items *'as medical equipment'* (Hannah). Another reason that technology was forgotten was because the children and their technology and the family had *'grown'* together (Bonnie, Celia, David) and it so was completely embedded in daily routine (Jenna, Deborah) that the family were so familiar with it that they did not even notice it (Jenna, Hannah, Grace, Daisy (sister), Colin) or catch *'it in the corner of… [their] eye'* anymore (Daisy, sister). This technology became just part of the children's *'stuff'* (Grace, Hannah) and *'as inconsequential as the kettle… [or] a bookshelf'* (Grace), especially when it was *'as much to help us [parents], as it is to help'* the children (Hannah).

In relation to the altered look of their homes, the visual impact of storage was the main factor that families struggled the most with. The space within the family home was impacted by *'massive'* (Bonnie, Grace) and *'cumbersome'* (Hannah, Faith) wheelchairs that are *'a metre long and two-foot-wide'* (Bonnie) (Image 4.2), home chairs (Image 4.9), shower chairs (Image 4.10) and trolleys (Image 4.11), walkers (Image 4.13), ventilators, oxygen concentrators (Image 4.1), oxygen cylinders (4.12) and profiling hospital beds (Images 4.6 – 4.8). Space or rather, the lack of it, was described as '*tricky…, particularly in the bedrooms'* (Grace). Deborah

talked of the *'sheer space'* that her children's wheelchairs take up in the house. Grace said that her son's *'home chair… was massive'.* Ruby (sister) said that her brother's home chair got in the way of her watching television, whilst Emma used a powerful metaphor to demonstrate the impact that her child's pea pod (seating equipment) has upon the look of the space in her home, noting '*our living room is quite small and Ethan's pea pod – it's like having a boat in the living room!'*

Ava (grandmother) explained how they had three chairs for different purposes and that if some equipment were better designed, then it could serve more than one purpose and reduce clutter in the home:

> *We've got the wheelchair, we've got the relaxing chair, we've got that big blue chair... It takes up all the room. You can't move sometimes for all the stuff. There's just not enough room for it all (Ava, grandmother).*

Although Colin said that the *'size of the equipment has often got smaller'* over time, families typically gained more technology over the years. Hannah explained that it is not *'just the equipment'* that causes the compression of space within the home but also the number of consumables this technology and equipment requires:

> *All the equipment also comes with supplies, so the equipment itself has an impact and you think, like, 'Oh well!' Whereas how much space they take up is not so bad, but when you add it all up with all this stuff that you need to make the stuff work, it's huge! (Hannah).*

All families spoke about the sheer amount of storage space required and this was a major problem throughout the house. All the families, even Emma and Hannah who both said that they lived in larger houses, were *'really struggling with space'* (Faith) and not knowing *'where they can put things'* (Jenna) '*because there is just so much stuff*' (Hannah).

Some families referred to their homes as looking more *'like a… storage facility'* (Emma) than a home because of the consumables such as nappies, feeds and medications. They knew that spares of certain equipment were essential to keep their child safe at home but described how storage was a genuine struggle. The scale and regularity of delivery meant that even the smaller disposable consumables created *'boxes and boxes of equipment and bits'* (Deborah). The eating and drinking and personal care consumables (gastrostomy MIC-KEY buttons, feeding pumps, milk, feeding containers and extension sets and nappies) had the biggest impact upon the look of the home in terms of delivery and storage and for disposal of the large

packaging used for delivery. Nappies are delivered in *'very large'* (Celia) *'absolutely huge [boxes] [laughs]… I could probably hide inside one, they are that big, you know?'* (Emma). Deborah, who had had a delivery of 12 boxes of nappies a few minutes before I arrived at their home told me how *'literally that whole [lounge] wall was covered in boxes [of nappies for her two children] [about 12-foot length] until [husband] took them upstairs'*. Some mothers talked of how service providers often want to reduce nappy deliveries from eight weeks to 12 weeks (Deborah, Emma), or 12 weeks to six-monthly but that parents literally have '*got nowhere to put them'* (Jenna).

Storage problems resulted in the loss of shared spaces in the home such as the conservatory because *'everything is sort of squashed in'* there (Faith). Indeed, even when the children lived downstairs, several families spoke about having an upstairs bedroom (often the room that would have been their child's bedroom) or even the whole *'upstairs of the house'* (Hannah) where *'everything is dumped'* (Jenna) that was *'literally floor to ceiling with boxes'* (Emma). No photographs of upstairs storage rooms were shared; perhaps they would have revealed private messy spaces or un-home like rooms that the families did not want me (or other people) to see.

Some families spoke about trying to have a home within the home for the technology and equipment, saying *'it all has like its own little special place'* (Grace), often finding *'a spare bit of floor'* (Bonnie), under or at the side of their child's bed (Image 4.12), on windowsills or stacked *'up against one of the walls'* (Deborah). Large equipment such as wheelchairs (Image 4.2), wheelchair frames and walkers (Image 4.13) and bulky consumables such as feed bottles were commonly kept out of the way in wet rooms or bathrooms when they were not being used *'because that's the only place that we can fit it… actually that's where its home is!'* (Hannah). Deborah, Celia and Isla said how they have at least one or two whole kitchen cupboards full of their child's medications and how when they get a *'delivery of prescriptions… [they] can't fit them all in [and]… have to just keep moving'* medications and feeds around their kitchen (Hannah), '*slowly trying to [laughs] get rid of stuff to make space to put the feeds in the kitchen'* (Celia). It is clear how much space and impact even relatively small consumables can have upon the look of the home.

Some families said that they had purchased cupboards and shelving units (Image 4.14), large sheds and even a caravan to store the equipment in or to *'hide'* it away so that it was *'not so glaringly obvious'* (Daisy, sister) and their home could '*look relatively fine'* (Grace). Both fathers (Colin, David) said that these strategies helped to make the technology, equipment and consumables as unobtrusive as possible whilst also creating a tidier, more organised and

functioning home. Having a tidy and organised home was important to families because the look of their home was also impacted by not having time for anything more than basic housework. Isla and Jenna said that decorating had been on hold for over eight years. Isla, Hannah, Emma and Amelia said that they cannot keep up-to-date with cleaning, clearing out worn, outgrown or unwanted household items, toys and clothes and organising some of the rooms in their home because they cannot leave their child in a room by themselves, even for a minute. David said that families *'still have to function within the home [and strive to] … store the equipment in a way that still allows… [their home] to be a home, as opposed to a hospital environment'.*

Some parents mentioned keeping furniture and clutter to a minimum and this thinking extended to refusing to take some discretionary specialist equipment that could be just *'another contraption'* (Amelia) that would take up space. The large mobilisation and seating equipment caused families to squash their lounge furniture into alcoves during the day, to create space for their child to be able to mobilise into the room to be with the rest of the family (Image 4.17). Some mothers said that their homes look '*really odd'* due to having to position their furniture to leave space for their child's technology such as their chairs (Emma) which *'are like a giant sofa bed'* (Hannah).

4.4.4 A home that sounds different

Although alarms on medical technology *'have to be insistent'* (Colin) to alert those caring for the children that immediate attention is needed, families cannot escape the '*low level*' (Hannah) *'constant'* (David) '*background*' (Hannah) sounds and alarms of the technology. Even though Emma, Deborah and Daisy (sister) said that home should be a place where family members can rest and relax, the sounds of the technology had a considerable and negative impact upon the ability of the family to feel at-ease in their home and their opportunities for physical, psychological and emotional rest and relaxation. Furthermore, parents often felt controlled by the sounds of the technology and equipment and this altered the feeling of home for them. Colin said that the technology and equipment *'makes a wonderful, wonderful slave and a diabolical master'* and added that the sounds of some technology and equipment are '*domineering [and] relentless… and because it is medical equipment, there isn't really a choice, is there? You have to use it!'*

Most parents expressed exasperation about the intrusiveness of the sounds of the feeding pump in their home. They could not understand why they were not given control of the sounds of this to suit their family's needs or why this type of technology could not have an escalating volume. The sound of the feeding pump was described by parents as being *'really irritating'*

(Emma) because of it *'screaming'* at them (Isla). Parents said that the feeding pump '*keeps beeping… It keeps going until you get up and sort it out'* (Jenna) corroborating Colin's description of this technology being *'domineering [and] relentless'.* Feeding pumps were talked of as being *'the one [piece of technology] that drives me the most mad*' (Isla) and *'the only piece of equipment that… annoys me… and gets on my nerves'* (Jenna) because, like Colin, David and Emma all said, the sounds from the feeding pump also disturbs their child's sleep. Despite triggering her son's epilepsy, Emma had been told that '*they won't turn… off*' the loud '*beeps… when you turn it on… when you attach the syringe… one minute before the end, [and]… again when it is finished'.* Like other parents, Isla wanted control over her son's feeding pump alarm and to have '*a remote-control button... and it would switch itself [alarm] off'.* Jenna implied that it was a postcode lottery as to whether you lived in an area where you had control over the feeding pump alarm:

> *I just wish that they could make a silent option like they do on a different brand of pump. It's just that we're stuck with this pump in this area… I know some pumps… you can programme to not make a noise when they've finished, and they've got like a pager, so it alerts the parent, but these don't (Jenna).*

Although parents said that they did not mind being woken up by the sounds of the technology that *'suddenly hit'* them when it was *'a genuine emergency'* (Colin), they hated the '*sound'* (Deborah) and *'noise'* (Hannah) of the *'annoying'* (Deborah), *'really high pitched'* (Faith) technology that *'will alarm for no reason'* (Hannah). Faith said that Finlay's oxygen saturation monitor triggers false alarms because of *'silly things like if he moves his hand or… the mask is not on… tight enough'*, whilst Deborah said that she must get up during the night to attend to her son Daniel's oxygen saturation monitor when his *'oxygen levels have dipped down… [only very] briefly'.* Faith, David and Deborah said that by the time they get to their son's bedrooms, their child's oxygen saturation levels have gone back up, so they have been woken up unnecessarily.

Parents cannot even gain restful sleep on the nights that their child is being cared for by night carers in another area of their house because they can still hear and are woken up by the sounds and alarms of respiratory and feeding equipment even though their child's bedroom is downstairs at the other end of the house. Faith said, *'even though you are not dealing with it, you are still hearing it'*. Hannah added that she is *'so used to being vigilant and on high alert, the noise… it really is hard to switch off at home.'* Being able to hear the technology when they are effectively off-duty results in parents feeling stressed and anxious about whether their child's health has deteriorated and whether they are about to be called to a life-saving

situation. Although Hannah wants the technology *'to alarm… if he [Hayden] has something wrong'*, there are '*times when… you would have to scrape me off the ceiling'* because of not being able to escape from the sounds of the technology in her home, even when carers are looking after her child.

Grace, Hannah and Emma talked about how the sounds of non-medical technology such as telephones and doorbells also impact upon their ability to be at-ease or relax inside and outside their home. Wireless doorbells (that carers use to alert them of their child's deterioration) and telephones have '*always got to be on loud, you could never have it on silent'* (Grace). Hannah and Grace spoke about their difficulty in *'switching off'* from responsibility for their sons' care, even when someone else is looking after them, because they are *'never not on call'* (Hannah) and said how exhausting this can be:

> *We have maybe just been sitting watching TV or something and the buzzer [from the wireless doorbell] goes 'Ding, Ding, Ding, Ding' and you are immediately… off your seat and half way down the stairs before your brain has sort of engaged to what you are going down to… It's like, 'Quick! Run! Run! Run! Run!' That's one of the things that's so exhausting, I think, on a day to day basis (Hannah).*

The impact of the sounds from the technology upon siblings varied. Emma explained that Ethan's brother *'completely panics when he hears a noise he doesn't know. He gets really worried about it. Which has only been since we've had Ethan'*. George's brother, however, was so *'familiar'* and *'comfortable'* with the sounds of the technology because he knew *'which machines make which noise'* (Grace) and was able to tell his mother which piece of technology is alarming. However, there seems to be a fine line with siblings being comfortable with the sounds of the technology and becoming desensitised to them. Isla explained that Isaac's brother does not react to the sounds from Isaac or his technology noting that he '*will still be eating dinner right next to Isaac [who was] … having a life-threatening, really bad choke'*.

It was clear that the technology and the children's health care needs altered the soundscape of homes, and thus, the feeling and meaning of home for the families. Although parents and siblings can escape the impact of the look of the extensions, adaptations and technology upon their home when they are asleep, they cannot escape the sounds of the technology. Some parents said that the sounds of the technology impacted upon their mental health and ability to feel at-ease and relaxed in their home more than how the technology impacted upon the look of their home.

4.4.5 Summary: Altered Physicality, Feeling and Meaning of Home

The technologies, equipment and consumables required by the children impacted upon the physicality, décor and furnishing of the homes and the space, and use of spaces, within their homes. Having a home that looked clinical and cluttered and more like a hospital or a storage facility than a home and not being able to escape the visual and auditory reminders of the fragility of their child's life impacted upon their ability to feel relaxed and at-ease in their home. Having little or no choice about the need for extensions, adaptations and technology meant that homes were changed and families whose adaptations had been fully funded by the local authority lost control of how their home looked and functioned. Some parents felt out of place in their own home.

4.5 Theme 2: The Presence of Carers in the Home

The needs of the children and their dependence on medical technology meant that families required the support of paid carers in their home to enable them to continue caring for their child at home. Although parents from some families and the older sibling became friends with their child's carers, in many cases the presence of these paid carers impacted upon the privacy and the function, meaning and feeling of home. The challenges that parents faced in their extra *'job'* (David) of finding, recruiting, retaining and training carers were clearly important to them and will be presented in this section.

4.5.1 Why carers are needed

The complexity of the children's health care needs made the children *'just really hard to look after'* (Emma). Most of the children required skilled, knowledgeable and expert *'full twenty-four-hour care'*, and they cannot be left *'for a second'* (Deborah) and need '*somebody with… [them] every second*' (Grace). Parents said that they cannot call upon relatives, friends, neighbours or a '*normal babysitter'* (Faith) to look after their child because their child's medical, technological and physical care needs are complex, complicated and often unpredictable, changeable and/or prone to deterioration. Emma said that parents like her *'are just from different worlds'* to parents who have typically developing children. Deborah agreed and said that parents cannot just hand their child '*over… to somebody else… [the carer has] got to know how to use every piece of equipment that goes with that child'*. She said that she cannot call upon other people to care for her children in an emergency:

> *It's not just like leaving a child with a neighbour and saying… 'They like peanut butter on their toast, and stick Peppa Pig on for them this afternoon, and these are the toys that they like playing with', It's much, much more than that! [laughs] (Deborah).*

Emma agreed and said that there was *'always something new to learn'*, whilst Faith said that more medical needs *'manifested'* as her child became older. Hannah said that their *'Complex Care Sister… said [that her service had]… never had a kid that has had such high significant, significant needs'.* Some of the children's conditions were so rare that they had not received a diagnosis or an estimate of life expectancy; however, most parents had been told not to expect their child to reach adulthood.

Parents talked of the impact of providing 24-hour care as being *'stressful'* (Grace) and how they were *'shattered'* (Emma), *'knackered'* (Faith, David), *'absolutely fried'* (Emma) and unable to *'function'* (Deborah). David spoke about living on a *'cliff edge'* and said that '*you are always walking on a tightrope*' when you care for a child who relies upon technology, whilst Grace spoke about having to '*juggle all the balls'*. Parents emphasised that they '*can't do it all'* (Deborah) and '*have to have that support… [They] wouldn't be able to do it [continue caring for their children] without the support within our home*' (David).

Only two families had the regular support of family carers such as their child's grandmother, or older brother or sister to help support their child's medical needs. However, family carers in five families did provide support for the sibling of the children who relied upon technology, for example, by picking them up from school, as a way of trying to support the family. Parents from two families specifically mentioned that they would not want their extended family members to provide care for their child even if they lived closer (David and Grace) as they did not *'want to put them [family, friends and neighbours] in that position [of being their child's carer]'* because of the risk of physical injury to their family member or the risk that their child might have a medical emergency or die in their care. Grace explained that '*it's not nice… doing resus[citation]… and there's a chance that you are going to lose him [George]'.* She also said that she did not '*want anybody to be in the situation where it could be them, because I would never ever speak to them ever again'* (Grace).

Even though families were initially *'very resistant'* (Faith) to having paid carers in their home, especially overnight, eight families had no choice but to accept support from agency, Direct Payment or Continuing Care carers, in order to *'survive'* (Hannah, Isla), not '*go under'* (Deborah) or *'come undone'* (Isla). These eight families had up to 26 paid carers working in their home for between 18 and 93 hours a week. Six of the eight families had waking night carers (carers who work during the night and must stay awake and be vigilant to the children's needs) for between three and seven nights a week. Even when the children's care only occurred downstairs, employing carers shifted the feeling of the home by the sense of intrusion

into the privacy of their home. The home gained characteristics of being a workplace because parents then had health and safety responsibilities towards these paid carers.

4.5.2 The home as a safe working environment for paid carers

Families had no choice but to accept adaptations and technology when they were employing carers because the moving and handling risks that parents could take could not be asked of carers. Hannah, Grace, David and Emma all spoke about having health and safety responsibilities towards their child's paid carers.

Hannah said that instead of thinking, *'I'll just carry him!'* when her son Hayden needed moving, having paid carers in her home meant that she had to have tracking and hoists fitted as carers must use them to protect themselves and Hayden from physical injury. Similarly, Grace said that she would have been happy for her son to have a typical bed, rather than a height adjustable *'hospital bed'* had it not been for the *'rules about bending and stuff that they [Occupational Therapy] have'.* Hannah spoke about obtaining mobilisation technology and equipment more quickly because of the health and safety responsibilities for the carers who are being paid to deliver care to her child in the home:

> *We have carers at home. So, we have a care package. There are people on duty who work nights to give him all the medical care that he needs… What I found is like, when it is just parents doing it, sometimes things can be quite slow moving, but when there's actually paid, employed staff coming in, then the equipment and the adaptations, and the funding moves along more quickly, because it has to, which I think that's partly why we've been able to get the equipment we need because if we need it, then the staff need it and the staff can't do their job if they don't have it (Hannah).*

Parents also spoke about having to ensure that the technology is serviced, and David spoke about technology which '*has to be safe for them to use, so hence why there's labels on of when it's been tested*'. Faith corroborated this saying that because she is '*employing carers… [she has] a duty of care for them'* and must maintain the tracking and hoists in her home. She spoke about having liability for the carers and said that they have no choice but to pay (around £500 per year) for the *'hoist insurance and servicing [because]… if we didn't maintain it [the tracking and hoists] and something happened to our carers then we could be liable!'*

Some parents mentioned how they also became responsible for the cost of training and/or training their child's carers *'how to use [their child's technology and equipment] properly'* and

'things like handling and lifting' (Faith) as part of their health and safety responsibilities. Parents disliked the responsibility of training carers and questioned whether they should be responsible for this extra *'job that we have to do'* (David). Parents said that they *'have to be trained'* and are not allowed to be *'let loose with'* the technology (David) or take their child and technology home from hospital until they *'pass… [their] competencies'* (Faith). However, parents were then expected to have retained the information about how to use the technology properly and correctly pass this onto other relatives and paid carers. Deborah found the responsibility of training others to use their child's Bi-Pap (ventilation) machine very stressful:

> *I found that really difficult because I felt that all the responsibility was on me to listen really carefully and make sure that I knew exactly what was what, because [Daniel] was going to be coming home the day after… It felt like too big a responsibility that I was then having to train somebody else… passing all that information over (Deborah).*

Parents said that they found it very difficult to find and recruit carers who were both medically and technically competent to be able to meet their child's care needs. Some families reported negative experiences of nurses feeding their children too quickly into their jejunostomy which could have been fatal. Although some families said that the feeding pump was easy to operate, Deborah spoke about the importance of *'getting over to people [about the]… serious complications [of feeding a child too quickly into their jejunostomy]'*.

Isla said carers can '*take months'* to acquire the necessary medical and technological competencies and really get to '*know*' their child so they could detect any deterioration in their child's health. Deborah explained how it takes regular contact with her children, who *'are very vulnerable… because they can't communicate'* and be able '*to pick up on those little, subtle, those little things? It's that side of things that concerns me'*.

Isla and Jenna both spoke about their dislike of recruiting suitable carers. Isla said that she *'absolutely hate[s] [recruiting carers]… I hate advertising… [and] I hate the interviewing… I have to work myself up to do it'.* Jenna had also put off advertising for carers, saying that she was worried about the calibre of applicants, *'I haven't done any advertising, just because I am a bit worried about who we will get, really'.* Although some families had some carers, particularly *'staff [who come] through Continuing Care'* (Emma) who had *'stayed for a long time'* (Faith) and thus, really knew their child, the retention of carers employed through agencies was a different matter. Grace explained why recruiting and retaining suitable carers is so difficult:

Carers come and go because it's so badly paid, and to be honest, they have a huge responsibility – I'd not be paid to do that… To see someone lifeless, like a dolly, to see someone not moving, like going a dramatic… very bad colour… to be paid £8 an hour [laughs] to do that, no way would I do it… It's a lifesaving role that they do. Not all the time – sometimes they do things just like being a babysitter and playing, with a bit of extra equipment around. But eyes in the back of your head, all the time! (Grace).

Other families said that it is hard to trust carers until the carer stops being '*anxious'* (Grace) and '*nervous'* (Emma) around their child. Parents said that they know that they are going to be called upon or woken up until the carer becomes really comfortable with their child and have handled a life-threating event *'right and manage it competently and feel secure in doing it'* (Isla).

4.5.3 The intrusion of paid carers into the privacy of home and family life

Even when carers are confident and competent to provide care for the children, they '*are not nurses'*, so families *'are not allowed to leave them [carers] on their own with'* (Emma) their child, for example, to attend parents' evenings at school or go out for a meal. One parent must always be present when the carers are on duty, because carers are not allowed to give medication, perform rescue procedures (Emma, Grace, Deborah) and are not *'officially… really supposed to touch a jej [jejunostomy], apart from using it to feed'* their child (Deborah). Seven mothers had given up work and two mothers had to reduce their work hours to part time because of the complexity of their child's medical needs. Consequently, mothers could not leave their home, even when paid carers were present, partially defeating the object of having carers in their home to provide them with some respite from caring.

Having paid carers in the house impacted upon individual, couple and family privacy and the parents and siblings' ability to use and control the space in their home as they wished. Grace said that family life *'is so out in the open. We have breakfast with the carers – there isn't a time that they're not in the same room'.* Emma and Deborah expressed annoyance and discomfort about the constant presence of carers due to feeling like they had to put on a public face to only reveal the parts of themselves that they wanted the carers to see. Emma explained that her *'house never feels like my house… [because] I can't relax… when I've got people here because there's people here that I don't really know'.* She described feeling trapped upstairs during the night when she cannot sleep because of feeling like she must put on a public face to talk to Ethan's carers:

> *So… if I couldn't sleep before, I would just come down and make a [drink] and then maybe sit in the living room and then go back to bed, but because there's people in with Ethan, I know that they will come in and start talking to me [laughs]… So, I just basically stay in bed lying awake, really annoyed that I can't come downstairs in my own house (Emma).*

Deborah also felt that she needed to alter her behaviour and communication as a result of the presence of carers:

> *It is quite hard finding some space to just be completely away from them [the carers] and you know, just do what you want to do without feeling like… I should be looking after them… or chatting with them… If I sit in here and read a book, are they going to think 'Oh she's a bit rude!'? (Deborah).*

Emma described how the carers conducting a professional role within her home altered her ability to feel relaxed in her home and to dress in the way that she wants, again suggesting that private activities are changed into public activities in the home when carers are present:

> *It's like [sighs], you know, when I used to be in work, I would come home sometimes if it had been a bit of a long day, and I would think 'Oh, I will just put my pyjamas on now'… and slob about to make tea, but because there are always people here, I feel like I can't do that in my actual house (Emma).*

Having carers intrude into the privacy of the home also impacted upon their child's siblings. Daisy (sister) described how *'it was strange at first [having]… carers coming into the house'*, whilst Emma said that Ethan's brother *'spends a lot of time in his bedroom now… as he's got older. It annoys him, as well, having people in the house'*. Deborah implied that her family only regains control of their home and the ability to feel at-ease once Deanna's and Daniel's carers have gone at night:

> *I wish that we could just take everybody's hands away from us as a family… and just shut the door and just be us... without everybody else intruding on that… We have got to have people coming in and intruding… but it is the place, too, where everybody goes away and leaves it to be just us, which is nice, which is important! (Deborah).*

Hannah, Emma and Faith attempted to mitigate the intrusion of carers into the privacy of their home by having their child cared for downstairs. Hannah, whose child has carers for six nights of the week, preferred her child being cared for downstairs from a *'privacy point of view. We*

go up the stairs and the carers are downstairs – they're not having to go up and down stairs and we've got a life up there that is kind of separate.'

Families often had no choice, however, but to have a home where their child's carers can *'just knock and come in'* rather than ringing the doorbell because parents cannot leave their children unattended to answer the door (Deborah). Deborah said that '*the new ones [carers] don't like it [not ringing the bell and being invited into the home]. They feel a bit nervous about it',* whilst Daisy (sister) also considered the impact for carers of intruding upon family privacy by saying that carers *'don't wanna be slap bang in the middle of everything'.*

The gaps '*at the top of the door for the hoist to go through'* (Celia) meant that family conversations (Emma) could be overheard by the carers. Intimacy between parents was impacted by the presence of carers. As Hannah said, *'it doesn't make for a romantic atmosphere, when there's someone sitting downstairs, you know [laughs]?'* Grace also explained *'it's like having your boyfriend round when you were with your mum [laughs]!'*

4.5.4 Summary: The Presence of Carers in the Home

The presence of carers in the home impacted family members in various ways. Parents did not want the extra role of becoming an employer for carers and did not want carers intruding into the privacy of their home, yet they needed the support of carers to remain physically, mentally and emotionally well enough to continue to provide safe care for their child at home with technology. Having carers present in their home meant that parents had no choice but to accept adaptations to their home, such as ramps, and certain types of technology and equipment, such as tracking and hoists, lifts and height adjustable beds, as they had to mitigate any risks to the carers associated with moving and handling. Parents had to accept health and safety responsibilities for the carers and were required to ensure that their home was a safe working environment for them. The presence of carers placed additional roles on the already exhausted parents; an ironic situation since parental exhaustion was often the reason for employing carers in the first place. The presence of carers resulted in parents and siblings feeling out-of-place at home due to feeling like they could not use or control the space in their home, or dress and behave in the way that they preferred or needed. As carers are not nurses who are professionally qualified to deal with medication and medical technology, parents are not allowed to leave them alone in the family home with their child, thus never gaining proper respite from caring which was one of the reasons for having carers in the first place.

4.6 Theme 3: Home is not Home without their Child

Parents said that home was the best place to meet their child's needs. Their child's hospitalisation had a negative impact upon all members of the family and family functioning. Home did not feel like home and their family did not feel like family when their child was not at home. Parents and the older sibling acknowledged that despite their resistance to the technology, equipment and consumables and the negative impact that these had for the look, sound, feeling and meaning of their home, they needed these for their child to live at home as part of their family and community. Each of these aspects will now be discussed.

4.6.1 Surviving or thriving: Hospital or home?

All ten families were explicit about wanting their child to live at home with them. David and Deborah, and Isla said that other options such as residential care would not meet their children's needs. Isla said that Isaac *'would not survive'* residential care because he is non-verbal, and staff cannot read his body language. Deborah explained that staff do not have *'a mum's instinct or that gut feeling that something's not quite right'*, and David noted that staff do not know the '*little quirks [and] what makes them [the children] tick'*. Even though Hannah, Colin, Deborah and Isla discussed how their child *'would have had to [live] in hospital'* had they been born *'10'* (Hannah) or *'20 years earlier'* (Colin) because their *'care needs are too significant to… have made it home'* (Hannah), none of the parents wanted their child to live or be in hospital. Hospitalisation was discussed as negatively impacting upon their children's development and quality of life, their own and their children's siblings' mental health, and family life. Despite this resistance, hospital was the only other place that Deborah, Hannah, Isla and David said that their child could live if they could not be cared for at home.

Although not classed as lifesaving, communication technology (Image 4.15) and leisure and/or play equipment (Image 4.16) were talked of as being vital for the children's health, wellbeing and development (Celia, Colin, Daisy, David, Deborah, Emma, Grace, Hannah, Jenna). Most family members said that their child *'can't thrive in hospital'* (Grace) because hospital was not a stimulating environment. Monkey (Child's chosen pseudonym) explained she gets *'upset'* when her *'communication aid is broken as I cannot talk to my friends'* and her mother (Celia) added that when this happens her daughter becomes *'very depressed because… she's not included then in conversations'*. Technology such as an iPad allowed wider family members such as siblings, grandparents and cousins who were geographically separated to speak to and see their child. Jacob used his iPad to ring his carer and grandmother, whilst Monkey used her iPad via her augmentative and alternative communication system eye pointer to access social media to talk by text to her cousins and friends, as she was non-verbal. The lack of play

opportunities, social interaction and the stark décor in the hospital results in children becoming *'institutionalised really quickly'* (Bonnie). Parents described their children as just being sat in bed when they are in hospital. They said that their children are not able to play on the specialist leisure equipment that they would play on at home, or '*get up and run around'* (Grace) when they are in hospital because of the risks of picking up secondary infections, and that this had a negative impact upon their children's development. Some parents said that compared with hospital, home is a better, more stimulating environment that gives their child the *'most experiences'* (Hannah). Grace saw home as a place where she could occupy George's *'mind with other things that are going to be good for learning'*.

Hospitalisation also had a negative impact for some of the siblings with Bonnie and Emma talking about the significant mental health impacts that occurred as a result of seeing their sibling and other *'really poorly'* children in hospital. Bonnie said that Ben's older brother was *'totally traumatised… [by seeing Ben] and every single child… in intensive care… really poorly'* and how *'he will not go to the hospital now. He'll 'phone and he'll FaceTime him but will not go to the hospital'.* Emma also said how Ethan's older brother was *'fine when he was really little'*, but is now *'terrified of nurses and doctors… [He] associates hospitals with people dying and being really poorly because he associates them with Ethan being ill'.* When Ethan's brother needed to be taken to hospital himself *'he couldn't cope at all'* (Emma). The importance of the children being cared for at home, whenever possible, protects siblings from exposure to seriously ill children. Bonnie spoke about the sensory aspects of hospital also traumatising her, even though she is an adult:

> *It is upsetting seeing… it's bad enough seeing your own, but when you're walking through a big unit and there's children… with chests open and on ECMOs and oscillators and the red bells are going, it's awful. And it does traumatise you (Bonnie).*

Parents also talked of the impact of hospitalisation on family life and feeling torn between meeting the needs of their hospitalised child and their other children because someone must stay in hospital with their child due to the complexity of their medical and technological needs. Deborah, who has three children – two with medical needs, added that *'life for us is hard when one is in hospital and one is at home because we're a bit torn – one of us has got to be with Daniel and one of us has got to be here at home with Deanna'.*

David spoke about going to extraordinary lengths to be a parent to all three of their children (one of whom does not have any medical needs):

We have had an occasion when Daniel was really poorly, on the year that Daisy [oldest daughter] was graduating… Deborah [wife] and I had all the arrangements in place to go down together, to watch her… together… [but then] Daniel was in hospital… and the only way that… we could do it was Deanna went into [children's hospice], I caught the train down… to watch Daisy… I jumped on the train to come back. As I got into [City], Deborah [wife] got on the train to go back down, and I used my mum and my auntie to sit with Daniel in hospital, while I then went back to the hospital. And we tend to do that, we tend, as much as we possibly can, we try to do it ourselves... it's hard (David).

4.6.2 Technology 'keeps us out of hospital' and enables 'us to stay as a family'

Families were willing to accept the negative impacts of technology if it meant that their child could live at home with them and if it helped prevent or reduce the duration of hospitalisation. Deborah explained that even though *'[some technology] stinks of hospital… it's a good thing… [because it] keeps us out of hospital… it does enable him to be at home'.* Parents had a love-hate relationship with the technology *'wishing that [they] didn't have to have'* it (Faith), whilst also being grateful for it because without it their child would not be alive (Grace, Hannah) or *'living at home'* with them (Hannah, Deborah). Celia, Faith and Jenna all said that the technology makes their life and caring for their child safer and easier, and Faith said that she *'couldn't live without it'.* Isla suggested that parents *'just have to come to the acceptance that you need this kit in your life, and if you haven't got it, then you are not going to have your life, really'.* Hannah added that the technology is *'as much to help us [parents], as it is to help [Hayden]*'. Deborah corroborated that the technology is *'vital… [and how] they are all meeting a purpose and the ultimate purpose is for us to have our children at home with us'.* Typically, as Bonnie explained, caring at home instead of in hospital made *'family life easier… [because] you're at home with your other children'* (Bonnie).

Respiratory technology was key to preventing hospitalisation or reducing the amount of time spent in hospital. David said that having the respiratory technology at home *'enables a quick transition from hospital back into the house'*. Deborah said that she *'was thrilled to bits'* that she could bring Daniel *'home [from hospital] when he's not completely well'* because they had all the technology that they needed to care for him at home. Deborah recalled a recent illness where Daniel would have been in hospital *'for two whole weeks'* had they not got the '*sat's [oxygen saturation] monitor… the oxygen concentrator and so forth'* at home. Faith also said that if she did not have Finley's *'ventilator and… oxygen'* at home that they would *'be in hospital quite a lot of times'*. Bonnie added that having a *'combination [of] Airvo… oxygen*

and… suction machine… equipment at home' meant Ben now had *'nowhere near as many'* hospital admissions and when he was hospitalised the amount of time that they would *'normally would be in hospital for [was reduced by] at least… six weeks'.* David, Deborah, Faith and Bonnie mentioned that fewer hospitalisations reduced NHS costs.

Mobilisation technology supported care at home and enabled the children and their family to access the outside world. Even though families were very resistant to tracking and hoists, this type of mobilisation technology became one of the favourite types of technology as it makes *'a massive difference to every day'* (Deborah). Families *'wouldn't be without'* (Celia) the tracking and hoists as they *'couldn't live'* (Daisy, sister), *'cope'* (Jenna) or *'function'* (David) without this *'amazing'* (Emma) technology. Deborah and Faith said that her children would '*be stuck… in bed'* without the mobilisation technology. Deborah elaborated that her children would be unable to go to school if their lift, wheelchair, tracking or hoists broke down, and she and David (father) would be unable to go to work. Family members said that the tracking, hoists and wheelchairs enabled the children to be showered and dressed and to go to a part of a house where they can be *'fully involved in the family space'* (Daisy, sister), rather than being confined to bed and thus, having a parent or carer with them in the bedroom at all times which would impact upon family functioning. Daisy (sister) said that the tracking, hoists, lift and wheelchairs have *'definitely helped me to stay more involved in their care',* highlighting how the technology can enhance access to much needed family support.

Despite some of the negative consequences of having the technology, equipment, consumables and paid carers in the home, parents said their home did not feel like home when their child was not there. Their child's absence altered the look, sounds and routines of the home. Three mothers spoke about their home feeling *'wrong'* (Deborah), *'odd'* (Emma) and *'eerie'* (Hannah) when their child was at school or in respite. Hannah explained how seeing Hayden's technology resulted in her feeling out of place downstairs when he goes into respite:

> *When he goes into respite, we drop him off and then we come home… We often just scurry away upstairs as soon as we come in, which if we were to stay down here, it seems kind of eerie to see all the equipment lying about when he is not there (Hannah).*

On the other hand, not seeing Ethan's seating or mobilisation equipment made Emma's house look empty when he was not at home:

The living room is really bare when Ethan isn't here because I have to leave space for his chairs. So, it looks fine when he's at home, but when he's not, it looks really odd, as if there is something missing (Emma).

Typically, their homes were busy places with people coming in and going out to help to support the care of their child and with the lights switched on all the time so that their child's health status can be constantly monitored (Grace, Deborah). Deborah said that her house '*just feels so wrong'* when her children go into the hospice:

It's our house and it's never dark. Because there is always somebody here… It's like constantly people in and out really, and yeah, busyness… there has always got to be somebody here… for Deanna and Daniel… It's like, this feels so wrong. It just doesn't feel right! (Deborah).

The technology enables the family to be a family. David said that the benefit of living at home with technology *'is that… the equipment enables us to… [maintain] our children at home… We are a family. [The technology] enables us to stay as a family.'*

4.6.3 Technology enables families to get out of the home and access their community

Despite home being a special and important place, families wanted to be able to get *'out and about'* rather than being *'stuck'* (Faith) and trapped in their houses. However, this was often challenging, especially as their child and the technology became bigger and heavier. Amelia, Isla and Hannah said that it is physically challenging to get their child ready to go out and then to manoeuvre them in their wheelchair. Families have to make sure that they have got everything when they go out shopping or they '*are not getting it'* (Isla) (and will have to go without any items that they have forgotten to purchase) because it is too difficult to keep loading and unloading their child into their wheelchair and van. Isla spoke about only being able to fill her car with fuel if there was a Pay at the Pump facility, as she could not leave her child *'in the van whilst… [she] ran into the petrol station to pay'* because of having to be constantly vigilant of his health and technological needs. Other families talked of the challenge of trying to *'get a couple of hours when… [they] can go out'* (Deborah) *'between… [their child's] medical care and all their equipment'* (Hannah).

The *'really marvellous'* (Colin) mobility technology enabled children and their families to access the outside world and was described by many family members as their favourite type of technology as it further enabled children to be included in family activities, socialise and be stimulated. David described his daughter as *'a heavy young lady'* whose wheelchair *'enables*

us to get out and function as a family'. The children who were non-verbal also enjoyed going out and both Bonnie and Deborah said that their children '*love'* going out. Jacob said that his wheelchair is his favourite piece of technology because of enabling him to go to one of his favourite places - the park - and chat to people. Jenna said Jacob's power chair gives him the independence to *'just have a drive around'* and be slightly in front of her and to *'stop and say hello to all the old people and all the dogs and all the babies'*. Hannah said that she wants Hayden to have *'the biggest amount of access into the community as… [it] is giving him the most experiences'.* Deborah spoke about how important it is for her children to be part of a community as well as a family:

> *[The technology] enables us to… still go out and access the community… we take them for meals out and walks out and days out, and go to theatres… Without that equipment, we wouldn't be able to do that – they'd be stuck in a bed. It gives them as normal a life as possible (Deborah).*

However, children and families cannot easily access the houses of family and friends once their children have *'really big'* (Isla) and very heavy power chairs. Celia and Emma said that other people's houses *'are completely inaccessible'* because they do not have enough space to *'accommodate… big wheelchairs'* and doorways are too narrow to fit the wheelchair through (Celia, Deborah). Other problems included *'the wheels [on a wheelchair not turning] like a pram's does'* (Emma) so the turning circle space to manoeuvre the wheelchair is inadequate. Also, *'electric wheelchairs… are ridiculously heavy'* (Daisy, sister) and cannot be lifted or tipped back over any steps (Emma, Hannah), and older children are too heavy to carry (Amelia, Celia). Consequently, Celia, Deborah, and Emma said that they have never been able to take their children to their family and friends' houses. Even when children and their family were invited to other people's houses for special events, the lack of accessibility led to them and their child feeling excluded and isolated. Celia explained how they were attending a party at a relative's house and how *'it was a good job that it was a nice day because you couldn't get into the house at all… we couldn't get in. So, [Daughter] was in the garden all day'.* Deborah said that *'it was very, very hard, at first'* not to be able to visit friends and family.

4.6.4 Summary: Home is not Home without their Child

Families talked of how home was the best place to meet their child's needs and give them a good quality of life. They also emphasised that their home does not feel like home without their child. Parents were willing to put up with the negative impacts that the adaptations and technology had upon their home and life at home because they wanted their child to live at home as part of their family. Residential care and hospital environments were not deemed to

be suitable for their child, and these environments had a detrimental impact upon the children, their siblings and parents, as well as for family life. Although the technology is vital for keeping the children alive and enabling them to live at home with their family, the mobilisation technology and respiratory technology were key for enabling the children to live at home and to access the outside world, albeit in a limited way. The respiratory technology helped prevent hospitalisation and reduced the amount of time spent in hospital and this made life easier for parents.

4.7 Conclusion

Parents had little or no choice but to accept the extensions, adaptations and technology because they wanted to be able to care for their child at home. Active involvement in decision making with architects, builders and health professionals who had regard for the house as a home for the whole family and who understood their child and family's immediate and future mobility, safety, privacy and dignity needs resulted in a stronger sense of feeling at-home. Families were willing to put up with the negative impact that the extensions, adaptations, technologies, equipment and consumables and the presence of carers had because they wanted their child to live at home as part of their family. Despite the challenges, home was not home without their child.

Chapter 5: Discussion

5.1 Introduction

Three themes were presented in the findings chapter: 1) Altered Physicality, Feeling and Meaning of Home; 2) The Presence of Carers in the Home; and 3) Home is not Home without their Child. These themes demonstrated how the alterations to the home and the presence of technology, equipment, consumables and carers impacted upon all aspects of the family members' lives, sometimes resulting in family members feeling like they were not at-home in their own home. As found by Buttimer (1976: 288), the findings demonstrated that family members are 'inseparably conjoined' with their environment.

The purpose of this chapter is to explore, integrate and present the study findings about how technology impacts upon the home and life at home with the wider literature. The search for a conceptual framework involved the consideration of the work of researchers from across a variety of disciplines. Authors who have written about the concept of at-homeness come from a health perspective (for example, Zingmark et al., 1995; Moore et al., 2010; Öhlén et al., 2014), a philosophical perspective (for example, Casey, 1993, 2001, 2009; Årestedt et al., 2016), a sociological perspective (for example, Mallett, 2004), a psychological approach (for example, Tuan, 1980; Scannell and Gifford, 2010, 2017; Lewicka, 2011), and a perspective that spans human geography and philosophy (Relph, 1976). However, it was Seamon, an experienced anthropologist and geographical educationist, whose work was the most relevant and applicable to the findings of this study. Seamon is described as 'one of the leading figures [and pioneers] in the phenomenology of place' (Lewicka, 2011: 223), having studied for over 40 years 'how people dwell on the earth and how they might dwell better' (Seamon 1979b: 40).

Seamon (1979a: 78, 1979b) states that there are five aspects that influence the attachment to home (for adults) and the 'experience of at-homeness'. The five aspects of at-homeness, 1) appropriation, 2) regeneration, 3) at-easeness, 4) rootedness and 5) warmth, resonated strongly with the accounts of the family members in my study. These five aspects enabled me to conceptualise the findings holistically and frame the discussion about how technology impacts upon the home and life at home.

The first aspect of at-homeness is appropriation. What Seamon (1979a) means when he talks of 'appropriation', is that a person has a sense of possession and control over their home space because they own that space and are in charge of it. He states that uninvited entrants and a lack of privacy can disrupt appropriation and can cause emotional responses of 'anger,

anxiety or discomfort' (Seamon, 1979a: 81). Whilst these negative emotional responses remain, a person cannot feel fully at home (Seamon, 1979a). Appropriation also applies to having 'places for things' so that a person has order over their living-space (Seamon, 1979a: 74). Objects become 'associated with a particular place' (Seamon, 1979a: 74). By keeping objects in familiar places, for example, on storage shelves or in drawers and cupboards, they can be located when they are needed without giving much thought about where they are (Seamon, 1979a). These objects and places generally go 'unnoticed and only come to attention when one fails to find something in its place' (Seamon, 1979a: 74).

The second aspect of at-homeness, regeneration, is when the home space has a restorative power for physical, emotional and psychological health and wellbeing. If the home is to be a place of regeneration, a person must have the opportunity to gain sleep and rest in it (Seamon, 1979a).

The third aspect is at-easeness. If the home is to be a place where people can experience at-easeness, a person must be able to feel physically, emotionally and psychologically 'comfortable and relaxed' enough to be themselves and act in a way that comes naturally to them (Seamon, 1979a: 87).

The fourth aspect of at-homeness, rootedness, which is unconscious (Buttimer, 1980; Tuan, 1980; Williams, 2002; Seamon and Sowers, 2008) and taken-for-granted (Buttimer, 1980) and is only brought to consciousness when the person's meaning of home is threatened, refers to the home 'providing a physical centre for departure and return' (Seamon, 1979a: 79). Rootedness takes time and includes the habits that are formed and the routines that take place in the home (Seamon, 1979a). A person who is rooted to their home knows that space intimately and saves mental energy by being able to move around and find objects within it without thinking.

The fifth aspect, warmth, is to do with both the physical and the emotional atmosphere of the home. Seamon (1979a: 84) suggests that a physically warm home is one that is ordered, clean, tidy and in good repair. Seamon (2017:3-4) continues to support this aspect of at-homeness, stating that we must 'care for and attend to place' because 'the quality of human life is intimately related to the quality of place in which that life unfolds, and vice versa'. Seamon (1979a: 84) stated that an emotionally warm home is one that is used and one that has 'an atmosphere of friendliness, concern and support'. Warmth is experienced physically, emotionally and precognitively (using the senses and not reason).

Seamon's (1979a, 1979b) five aspects of at-homeness theory will now be integrated with the three themes presented in the findings chapter. Figure 5.1 shows how the three themes relate to these five aspects of at-homeness and provides a brief definition for each of these five aspects.

Theme 1 *(Altered physicality, feeling and meaning of the home)* presented challenges to all five aspects of at-homeness (appropriation, regeneration, at-easeness, rootedness, and warmth) for both children using medical technology and their family members. Appropriation was challenged when families could not refuse the way that adaptations were made to their home when these were fully funded by a Disabled Facilities Grant. Regeneration was impacted as the families lacked opportunities to gain sleep, rest and rejuvenate because of their child's medical needs, the sounds of the technology and the constant presence of carers in the home. Being at-ease was difficult because family members could not be themselves or act in a way that came naturally to them in their home because carers were always present. Their sense of rootedness, the gradual process of becoming familiar, comfortable and attached to their home was interrupted or altered each time a new piece of technology or equipment was introduced. The warmth of their home was thwarted by the wear and tear caused by the technology and equipment which meant that the families could not have cosy furnishings in the areas of their home accessed by their child.

Theme 2 *(The presence of carers in the home)* presented the challenges to three aspects of at-homeness (appropriation, regeneration and at-easeness). A lack of appropriation was evident as the families could not refuse adaptations and technology because of their child's needs and their health and safety responsibilities to their child's carers. The potential for regeneration was disrupted even when carers were present in the home, as the parents were always 'on call' and therefore could not gain proper rest and relaxation to recuperate. At-easeness was disrupted as parents felt like they must put on a public face so as not to appear rude or lazy in front of their child's carers.

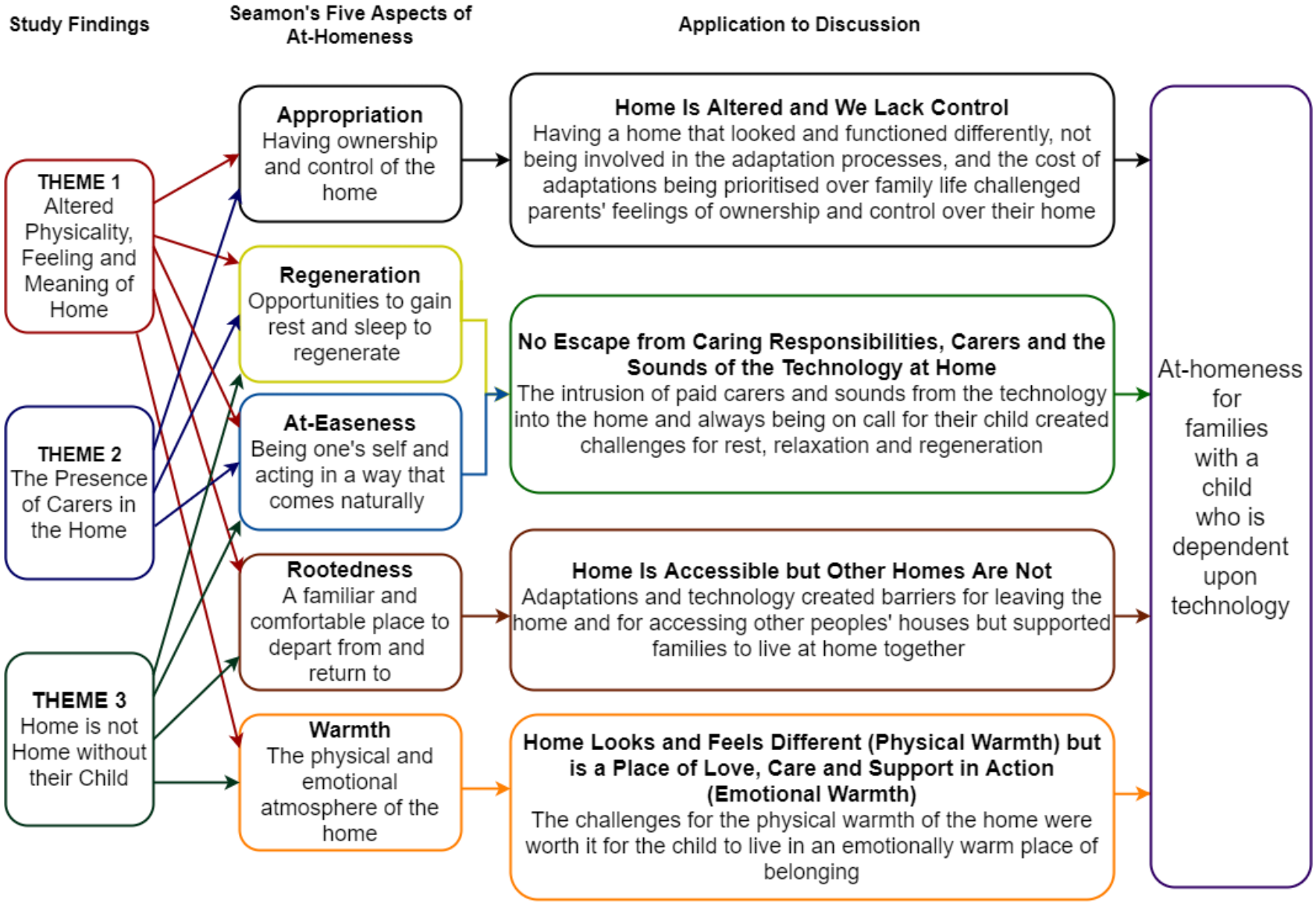
Theme 3 *(Home is not home without their child)* presented how families could experience at-homeness despite the challenges to three aspects of at-homeness (regeneration, rootedness and warmth). Although the adaptations and technology could be disruptive, they also helped establish a sense of rootedness as they enabled the children to be included in shared areas of the home, and the children and their family to access their community. The adaptations and technology also enabled a sense of warmth and rootedness as they helped families to care for their child at home rather than needing to be in hospital all the time. Parents talked of how home was the best place of care for their child and how they had more control of their child's

care than if their child was in hospital. Home was a place where their child was known and valued and a place where the social interaction and stimulation that their child received had a positive impact upon their health and development.

Figure 5.1 shows how the five aspects of at-homeness have been applied to frame this discussion chapter. The discussion explores both the challenges to at-homeness and how at-homeness was achieved despite these challenges. It is presented under four key headings: Home is Altered and We Lack Control (Appropriation), No Escape from Caring Responsibilities, Carers and the Sounds of the Technology at Home (Regeneration and At-Easeness), Home is Accessible but Other Homes are Not (Rootedness), and Home Looks and Feels Different (Physical Warmth) but is a Place of Love, Care and Support in Action (Emotional Warmth). The findings about how living with technology impacts upon the regeneration and at-easeness aspects of at homeness (Seamon, 1979a) are presented together because they were found to be so closely entwined.

Whilst drawing heavily on Seamon's work, work from other authors and disciplines is utilised. The work of other phenomenological human geographers (Relph, 1976; Buttimer, 1980; Tuan, 1980) and the literature about place attachment (Scannell and Gifford, 2010, 2017; Lewicka, 2011), and the meaning (Mallett, 2004) and feeling of home (Zingmark, Norberg and Sandman, 1995; Manzo, 2003) and the influence of children's medical technology (Moore et al., 2010; Lindahl and Lindblad, 2011, 2013; Dunbar et al., 2019; Lindahl and Kirk, 2018) is drawn upon. The literature about adults living in residential (Saarnio et al., 2017), hospice (Rasmussen and Edvardsson, 2007) or therapeutic institutional care (Lawson, 2018), and adults living with chronic illness (Öhlén et al., 2014; Årestedt et al., 2016) or bereavement in later life (Cristoforetti, Gennai and Rodeschini, 2011) will be also be referred to for comparison with their experiences of at-homeness, as will the wider literature relating to the experiences of parents caring for children with complex medical needs at home (Sobotka et al., 2019; Toly et al., 2019; Toly, Blanchette and Musil, 2019; Boss et al., 2020).

Figure 5.1 Application of study findings to Seamon's (1979) five aspects of at-homeness



5.2 Home is Altered, and We Lack Control (Appropriation)

The ownership and control aspect of 'at-homeness' is referred to by Seamon (1979: 80) as 'appropriation'. One of the meanings of home for the parents in this study was that home should be a place where they were *'in control'*. As family members used the terminologies of *'control'* and *'ownership'* and implied 'possession' of their homes, their terms will be used instead of appropriation to align with their accounts.

For those raising children with life-limiting conditions, the home is commonly perceived to be 'a gold standard place of care and comfort' (Dunbar et al., 2019: 104) where family members can feel more in control than being in hospital (Kirk and Glendinning, 2004; Cockett, 2012; Higginson et al., 2013). However, as presented in Theme 1 of the findings, living with medical technology often challenged parents' sense of ownership, possession and control over their home. This section will discuss these aspects.

5.2.1 Home looks different

Like the findings of other studies (Cockett, 2012; Alsaleh et al., 2014; González et al., 2017), all the parents wanted to care for their child at home. All the parents also felt that health and social care professionals had assumed that home was the place that they wanted to be with their child without consulting them. Furthermore, as found in previous studies (Kirk and Glendinning, 2004; Eaton, 2008; Mitchell et al., 2016), parents did not believe that their child would survive in residential care environments because of the lack of staff with the medical and technological skills required.

Parents felt mixed emotions about caring for their child at home. They wanted their child at home but disliked their home functioning, feeling, sounding and looking like a hospital or logistics company storage facility. Having an altered home challenged families' sense of control over their home. Having a home that looks like a hospital is widely reported in the literature about families who have technology-dependent children (Lindahl and Lindblad, 2011; de Lima, de Paulo and Higarashi, 2015; Paddeu et al., 2015). However, having a home that families described as looking like a logistics company's storage facility is a new finding. The visual impact of the storage of technology, equipment and large number of consumables that compressed the space within the home was the factor about living with technology that all the families struggled with the most. It was this factor that reminded parents and one of the siblings that their home is different to the homes of other families, as also reported by Moore et al. (2010). This finding highlights why Lindahl and Kirk's (2018: 7) suggestion 'of ensuring that the design or any refurbishments integrates the technology into the existing style of the home and fits with habits of social interactions' is so important.

Similar to the findings from other studies, having a home where they felt so out of place and that looked different to other homes led to some parents experiencing and displaying signs of stress, anxiety (Nicholl et al., 2013; de Lima, de Paulo and Higarashi, 2015; Edelstein et al., 2017), and grief and loss over how their home used to look before they had their child (Williams, 2002; Årestedt et al., 2016). Their desire for a home that looked like other homes rather than a hospital or storage facility, and not having any choice about this created tension for parents. This tension has also been described by Cockett (2012).

The parents all strove to live a family life like those of families who do not have technology-dependent children, as seen in findings from other studies (Rehm and Bradley, 2005b; Moore et al., 2010; Lindahl and Lindblad, 2011; Cockett, 2012). Although they recognised that their family did not live in *'the way your normal family would live'*, parents did not want to experience 'othering'[19], as described by Spivak (1985) and Riggins (1997), from their extended family members, friends, paid carers or strangers because of the public areas of their home appearing different to those of families who do not have a technology-dependent child: having adaptations such as ramps, tracking and hoists and their child's bedroom downstairs made their home appear different to other homes. This finding aligns to other studies which revealed parental concerns about 'an excessive appearance of disability' (Michalko, 2009: 65) and the 'public stare' (Jones, 2013: 33) of visitors to the home.

Previous literature focuses upon the strategies that families use to conceal the technology inside the house (Carnevale, 2007; Moore et al., 2010; Carter et al., 2016). Indeed, like the families in other studies (Levine, 2005; Carnevale et al., 2006; Toly et al., 2017; Woodgate et al., 2015), parents and an older sibling said that good technology is that which can be disguised in order to distract attention away from how dull, unattractive and intrusive the technology, equipment and consumables can be. Parents hid the technology, equipment and consumables away from shared areas of the home as best they could to reduce the sense of aesthetic degradation and to retain control over how their home looked to people from the outside world (visitors to the home).

However, some of the large mobilisation and seating equipment could not be hidden or camouflaged, and it intruded and took control of the space in the home. Similar to the findings

[19] To experience oppression and discrimination and to be 'disqualified from full social acceptance' because of 'the divisive nature of social structure – reflections of the social divisions of class, race, gender, age, disability and sexual identity' (Thompson, 2006: 269/15).

of Kirk, Glendinning and Callery's (2005) study with parents of technology-dependent children, a young sibling spoke about her brother's home chair getting in the way of her watching television. These findings resonated with those of other studies which report that technology, equipment and consumables can negatively impact upon the space in the home and that parents can face difficulties in positioning (de Lima et al., 2015), storing (O'Brien, 2001; Heaton et al., 2005; Lindahl and Lindblad, 2011), and hiding or camouflaging it (Carnevale et al., 2006). Parents did not want their homes to look different to those of families who do not have children who rely upon technology.

5.2.2 Forced adaptations: losing control

Seamon (2017) has spoken about quality of life being related to the quality of place and vice versa. There is a paucity of knowledge about how having adaptations to the home and living with technology can impact upon the home and feeling at-home for family members who have children with complex health care needs and medical technology. This study presents new findings in that the families who had their adaptations fully funded by a Disabled Facilities Grant and who had contractors appointed by their local authority reported worse experiences and outcomes of having their homes adapted than those who funded or partially funded them and appointed contractors themselves. The families who received a Disabled Facilities Grant reported not being involved or listened to in the application, planning and building processes and felt cost was prioritised over their child and family's health, wellbeing and family life. This study extends Seamon's work as it reveals that parents felt frustrated, angry and like they had lost ownership and control over their home, even long after 'uninvited entrants' (Seamon 1979a: 81) to their home, like council architects and builders, had gone. The cause of these negative experiences and outcomes will now be explored.

All ten families owned, rather than rented their home and had lived in their homes for around a decade or more. Research about residence length and home ownership show that these are both consistent predictors of place attachment – the bonds that a person has with a place (Scannell and Gifford, 2010; Lewicka, 2011). Parents and the older sibling said that they had no choice but to accept the adaptations and technology if they were to be able to care for their child at home. Parents from the families who received Disabled Facilities Grant funding felt powerless when staff did not consider that their house had been a home for many years. Eight of the families had made a significant emotional and financial investment into their home, which had been purchased as a place of permanence before they had their child. It is this 'emotional and financial investment' in the home that Lewicka (2011: 225) states is a 'positive predictor of attachment to the home'. It was evident that attachments to the home were altered when the homes that families had been working hard to buy were described as being *'taken*

away from' them as a result of not having control over Disabled Facilities Grant adaptations. This finding extends Seamon's (1979a) appropriation aspect of at-homeness by adding knowledge that the negative memories of lacking autonomy and control over the adaptations can result in the family members of children who are technology-dependent feeling an enduring loss of control over their home. It further suggests that this loss of control is experienced as a sense of alienation from their home. Relph (1976) refers to this as existential outsideness, which is an inability to feel fully immersed in a place.

As stated by Castor et al. (2018), to strengthen family life and promote the health of all the family members, families of sick children require trusting alliances and shared decision making with health care professionals. Parents felt powerless when they were 'silenced' (Currie and Szabo, 2019: 1251) by care providers, and when those involved in the adaptation processes did not have the required attitude, knowledge, skills and understanding about the needs of their family. This was a finding that resonates with the reports of children, siblings and parents who took part in Castor et al's (2018) study, and those of parents of children with serious disabilities who took part in Dybwik et al. (2011) and Brinchmann's (2005) studies. Despite the evidence that not being involved in decision making impacts upon autonomy (Sine, 2015) and that poor communication between professionals and the parents of children with disabilities can be problematic for home adaptation outcomes (Boniface and Morgan, 2017), the families who received fully funded Disabled Facilities Grant adaptations reported that they were not involved or listened to in the application, planning and building processes. Not being involved in decision making resulted in the Disabled Facilities Grant adaptations not being well thought out and not suiting the long-term health, wellbeing and accessibility needs, daily routines and functioning of the children and their families.

Typically in the United Kingdom, homes with two or more floors have bedrooms upstairs, and bedrooms are perceived as private areas that do not have to be 'staged for the eye of the visitor' (Soaita and McKee, 2020: 8). However, families with Disabled Facilities Grant adaptations had the location of their child's bedroom dictated to them. Its location downstairs caused distress for more than half of mothers because it felt alien and less safe for their child to be separate from them. This was a finding that aligned with those of Dunbar et al. (2019: 104) who state that safety is a recurring factor in place 'belongingness'. The physical distance from their child was problematic, especially at night, as parents needed to be constantly vigilant and available to attend to their child's health and technological needs, even when paid carers were responsible for their child's care.

The appropriation and rootedness (5.4) aspects of at-homeness, as described by Seamon (1979), are clearly evident in the findings. Not being able to move around their home freely and having to, for example, move large and heavy items of furniture like their child's bed to be able to take their child out into the garden resulted in some mothers feeling frustrated with, and being disturbed by, the changes to their home. These mothers felt out of place in their home for years after the changes were made. This finding supports Seamon's (1980) theory that the home environment needs to be compatible with the time-space routines that occur within it. The findings reveal a unique contribution to knowledge about how families need to have control over their home and to be involved in decision making about the changes to their own home. Involving parents should help to ensure that adaptations are compatible with family functioning, because the impact of negative adaptations can influence how parents feel about their home decades later.

As with the families in this study, other researchers have reported that families have to fight for (Currie and Szabo, 2019; Boss et al., 2020), prove they are deserving of, and wait for resources (Dybwik et al., 2011) and adaptations (Boniface and Morgan, 2017) that they need to be able to care for their child at home. However, despite their resistance to and ongoing frustration with some adaptations, parents were extremely grateful for them because they enabled them to live with their child at home as a family. Parents knew how costly the adaptations were and wanted them to be long-lasting to avoid wasting taxpayer's money by their child growing out of them and having to apply for more funding. They were aware that health and social care professionals were operating within bureaucratic systems and, like them, had to fight to justify their child's immediate and future need when making applications for funding. Parents were also aware that the people who approve the funding for adaptations also need to be accountable for the spending of public money. However, although parents were aware that health and social care professionals were operating within these challenges that have previously been reported (Kirk and Glendinning, 2004; Mansell and Beadle-Brown, 2005; Bourke-Taylor, Cotter and Stephan, 2014), they felt it unjust when they were stuck with poor workmanship, adaptations and room layouts that had been made in the quickest and cheapest way possible, especially given the amount of money that they save the NHS by caring for their child at home.

Parents were clearly anxious about the prospect of losing control over their home and potential future stress associated with further adaptations, resonating with Boniface and Morgan (2017) and Bourke-Taylor et al.'s (2014) findings. Moving to a new house when they had a child reliant upon technology and constant care was not a realistic option for the families, meaning adaptations were inevitable. The 'permanent' disfigurement of adaptations - the degradation

of aesthetic - made the home look very different to other houses; this was perceived to reduce the saleability of their home. Like one mother said, *'who wants a house with a lift in it?'*

5.2.3 Summary (Appropriation)

The findings on appropriation in this study have shown how the families of children who rely upon technology can face challenges to retaining possession, ownership and control over their home. No other literature could be found that considers how these challenges impact on families achieving a sense of appropriation.

New findings from this study relate to the sense that home looked like a storage facility and highlights the lack of control and involvement that families had in the adaptations that were made to their home. This study further contributes by supporting Seamon's (1980) theory that the home environment needs to be compatible with the time-space routines that occur within it. This compatibility was limited, especially for the families who had Disabled Facilities Grant adaptations, some of whom still felt out of place in their home long after the adaptations had been made. This disruption to appropriation was not as evident where families had more control over the adaptations; these families expressed a stronger sense of at-homeness. This exploration of appropriation adds depth to existing knowledge about the families' desire to hide or disguise some of the adaptations, technology, equipment and consumables out of public sight as best they can as a strategy to retain control over the look of their home.

5.3 No Escape from Caring Responsibilities, Carers and the Sounds of the Technology at Home (Regeneration and At-Easeness)

Seamon (1979a: 81) 'refers to the restorative powers of the home' for physical, emotional and psychological health and wellbeing as the 'regeneration' aspect of at-homeness. By this he means the opportunity to gain sleep and physical rest in the home. Similarly, 'at-easeness' occurs when a person feels physically, emotionally and psychologically 'comfortable and relaxed' enough to be themselves and act in the way that comes naturally to them, rather than putting on a public face, only revealing what they want other people to see and 'to maintain a particular… image' (Seamon, 1979a: 83/87). In this section of the discussion, regeneration and at-easeness are presented together. Although they are discrete aspects in Seamon's writing, within this study they were found to be so closely entwined that they are discussed together.

Seamon's (1979a, 1979b) theory of at-homeness sometimes presents a somewhat idealised or aspirational notion of home, for example, his at-easeness and regeneration aspects of at-homeness presume that the inside world of a home is a private space that can be a place of

refuge. Whilst this may be the case for many families it is not so for all families and it was not the case for the families in this study.

Seamon's theory predates the advances in intensive care, medical science, technology and clinical expertise that led to children being cared for in their family homes. Despite being a more restful place than hospital, the homes of the families in this study were not always a place of privacy where family members felt comfortable and relaxed enough to gain rest and regeneration. Like Boss et al.'s (2020) findings with parents who care for their children with medical complexity at home, parents in this study reported not being able to close their door to carers to have private family time. Parents and the older sibling wanted their home to be a place for regeneration and ease, as has been reported in the literature for over two decades (Zingmark, Norberg and Sandman, 1995; Rasmussen and Edvardsson, 2007; Årestedt et al., 2016; Israelsson-Skogsberg et al., 2018). Although family members reported that home-based care was better for their health and wellbeing and the functioning of their family than being in hospital - findings which resonate with those of Castor et al. (2018) - there were three reasons why the homes of the families were not always places of 'regeneration' and 'at-easeness'. These reasons were the: 1) constant presence of paid carers in the home; 2) parents always being on call for their child because carers are not nurses and cannot be left alone in the house with their child, and; 3) there being no escape from the sounds of the technology. Each of these challenges to at-easeness and regeneration will now be discussed.

5.3.1 The presence of paid carers in the home

The intrusion of paid agency, Direct Payment or Continuing Care carers challenged parents' and siblings' ability to achieve what Seamon (1979a) refers to as the at-easeness and regeneration aspects of at-homeness. Parents described having conflicting emotions about not wanting paid carers intruding into the privacy of their home but having no choice but to accept the support of carers because without this support they could not remain physically, mentally and emotionally well enough to continue providing safe care for their child(ren) at home. This finding resonates with previous studies of parents caring for children with complex medical needs at home (Nygård and Clancy, 2018; Currie and Szabo, 2019; Dunbar, Carter and Brown, 2019; Boss et al., 2020).

The desire for home to be a restful and peaceful family place where family members can relax and be themselves to gain rest and regeneration has been found to be an important aspect of at-homeness for children and adults in the general population (Zingmark, Norberg and Sandman, 1995). This desire for home to be a restful and relaxing place has also been found in families who have children who require home mechanical ventilation (Israelsson-Skogsberg

et al., 2018). It is also evident in studies of adults living with chronic illness (Årestedt et al., 2016), adults living in therapeutic communities (Lawson, 2018) or residential care (Saarnio et al., 2017), and adults in receipt of palliative care (Rasmussen and Edvardsson, 2007).

Introducing formal care to the home space altered the atmosphere and the meaning of home because home was no longer a private place for the families, as reported by other researchers (Milligan, 2000, 2003; Lindahl and Kirk, 2018; Repo, 2019; Boss et al., 2020; Camara and Callum, 2020). Årestedt et al. (2016: 4-5) state that 'places that mean well-being for families … can … be places where the family members… can feel relief [and] are able to relax and be themselves… where there are no demands, and they can just do nothing at all', suggesting that the homes of the families in this study could not always be places of wellbeing.

Several mothers reported difficulties in finding a space in their home where they could be completely alone and able to relax when carers were responsible for looking after their child. This finding is similar to those of previous studies with families of children with complex health care needs which report that parents can feel uncomfortable about their family and social interactions taking place in front of professionals and carers (Lindahl and Lindblad, 2011; Samwell, 2012; Boss et al., 2020). Mothers could no longer be themselves or use the space in their home as they wished because, like the findings of other studies (Wang and Barnard, 2004; Paddeu et al., 2015), the previously private, family place had become a public space where they felt watched or scrutinised by their child's carers. Mothers said that they could not relax in the shared family spaces of their home when carers are present because, as Årestedt et al. (2016) also reported, they felt like they must talk to carers and put on a public face, for fear of being judged as rude or lazy by the carers who were looking after their child. These findings were also identified in previous studies with parents who have children who are dependent upon technology (Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011; Currie and Szabo, 2019).

Family members felt unable to act as themselves because of the intrusion of carers in their home. Other studies have reported the intrusive impact of carers upon individual, couple and family privacy (Dybwik et al., 2011; Nicholl et al., 2013; Toly et al., 2017; Lindahl and Kirk, 2018), the psychological and emotional wellbeing of parents (Nicholl et al., 2013; Årestedt et al., 2016; Lindahl and Kirk, 2018), and siblings (Diehl, Moffitt and Wade, 1991; Toly et al., 2017), and the structure of and functioning of the family (Nicholl et al., 2013; Paddeu et al., 2015; Toly et al., 2017). Castor et al. (2018) found being at home eased stress for siblings because they could continue their own lives. Being at home had other benefits for siblings who, like the siblings in Diehl, Moffitt and Wade's (1991) study, had become fearful of doctors

since seeing their brother or sister and other children in hospital. As reported by Wang and Barnard (2004: 40), hospital is a place where 'life and death is the centre of everyday activity'. However, not being able to be themselves or use the spaces in their homes because of the presence of carers caused parents and siblings emotional responses of annoyance and discomfort and resulted in them feeling out of place in their own home. This was a finding that supports those of other researchers who have explored the experiences of families caring for a ventilator-dependent child or adult with complex health care needs at home (Dybwik et al., 2011; Lindahl and Lindblad, 2011) or of older adults who are cared for in their homes (Milligan, 2003; Repo, 2019).

The presence of carers downstairs meant that couple intimacy was impacted, as reported previously (Kirk, Glendinning and Callery, 2005; Sine, 2015; Boss et al., 2020), with one mother voicing concerns about whether her marriage would last because of this intrusion. There is strong evidence that parents of technology-dependent children are more likely to separate or divorce than the general population (Kirk and Glendinning, 2002; Carnevale et al., 2006; Paddeu et al., 2015; González et al., 2017). However, whether this was a result of the lack of privacy, the tiredness or exhaustion, the lack of time to spend quality time together or to attend to their own health and social care needs, or a combination of all of these is unclear.

Parents divided their homes into private and professional areas to retain control over their privacy. This finding resonates with those of Lindahl and Kirk (2018) and Lindahl and Lindblad (2013) who also explored the ways in which parents of children with life-limiting conditions demarcated public and private zones in their homes. Some of the families who had waking night carers accepted that, especially at night, downstairs was the domain of the carers. The families who kept the upstairs of their homes as private spaces felt more at-ease, more able to relax and regenerate (Seamon, 1979a) than when they were downstairs where they felt overseen by carers. This may have related to upstairs being particularly 'loaded with more private values' than downstairs (Lindahl and Kirk, 2018: 2) and being a place where they, like families in other studies (Dunbar et al., 2019), felt like they belonged. These findings resonate with those of Årestedt et al. (2016: 8) that there are 'specific places in the home that are more related to well-being than others'.

5.3.2 Parents are always on call for their child

The second factor to impact upon the regeneration and at-easeness aspects of at-homeness was that parents were always on call for their child, even when paid carers were responsible for their care or when their child was at school. This finding resonates with those of other studies of children with complex health or technology needs (Hobson and Noyes, 2011; Currie

and Szabo, 2019; Wilkinson, Bray, *et al.*, 2020). Almost all the families lacked practical, physical and emotional support from their extended family and friends, also aligning with the findings of other studies (Hobson and Noyes, 2011; Paddeu et al., 2015; González et al., 2017; Toly, Blanchette and Musil, 2019). As seen in other studies, parents lacked support because of geographical separation (Hobson and Noyes, 2011), or because their extended family members feared taking responsibility for their child's care (or the parents were fearful of them taking responsibility) (Diehl, Moffitt and Wade, 1991; Hobson and Noyes, 2011), or because they lacked the physical ability to provide care for their child (O'Brien, 2001). A new finding of this study was that two families did not want to put the responsibility of their child's care onto their extended family members in case their child died in their care because they would never be able to forgive them. This meant that formal respite was the only option for most of the families to gain rest and regeneration.

Although the purpose of having paid carers was to provide respite for the parents, this purpose was not fulfilled since carers are not qualified nurses and, as such, could not be left alone in the house with the technology-dependent child. Carers are not medically qualified and are therefore restricted in the duties they can undertake. They are not allowed to give medication or touch a child's jejunostomy, apart from using it to feed the children, despite these needs only being classed as low or moderate by the National Framework for Children and Young People's Continuing Care (Department of Health, 2016). As such, even when carers are responsible for the child's care, at least one parent or appropriately trained and competent family member had to be available in case their child had a medical or technological emergency. Parents have 24-hour responsibility unlike nurses who Carter and Bray (2017) report can escape the pressure of providing care for technology-dependent children at the end of their shift. Like the mothers of infants with complex congenital heart disease who took part in Imperial-Perez and Heilemann's (2019: 356) study, parents 'could not walk away from… or ignore' their child's needs, and as reported by other researchers (Lindahl and Lindblad, 2011; Chiang and Amin, 2020), this meant that parents could never switch off. As Rehm and Bradley (2005a: 815) had found, parents 'reached a point where … [they] don't know how to relax'. Parents require a restorative environment and a break from being constantly vigilant to their child's needs and watching over the actions of carers (Lindahl and Lindblad, 2013) to recover from their stress and fatigue and to restore their physical and mental health and wellbeing. Parents talked of their home as being a place of work for both them and their child's paid carers. This framing by parents of the house as a place of work has also been reported by Milligan (2000) and Lindahl and Kirk (2018). Not being able to obtain total respite from caring for their child impacted negatively upon the home being a place of regeneration and at-easeness for parents.

5.3.3 No escape from the sounds of the technology and equipment

Seamon (1979: 81-82) states that 'the home houses physical rest… [and] psychological regeneration'. However, parents did not have any control over the tone, volume and sounds of the technology. A parent of a child with medical complexity who took part in Boss et al.'s (2020: 180) study found 'the home setting … [to be] more conducive to healing because there's less interruptions'. However, family members in my study could never escape from the 'audibly apparent' (Moore et al., 2010: 4) constant background sounds and domineering alarms from the essential life-saving and non-medical technology and equipment. As found by other studies, the sounds of the alarms are one of the greatest contributors to parental sleep deprivation (Heaton et al., 2005; Keilty, 2015; Spratling and Lee, 2020). The meaning of home was altered as a result of family members not being able to obtain the rest or relaxation in their home that they so desperately needed to regenerate. Although some literature reports that noise from the technology can 'be a problem' for parents (Cockett, 2012: 33) and annoying for children (Israelsson-Skogsberg et al., 2018), this is the first study to specifically report how the intrusion of noise from the technology into the home impacts upon the home being a place of regeneration and at-easeness. However, Lindahl and Kirk (2018: 11) do discuss how the sounds of the home can influence how families conceptualise their 'place and space'. On a related note, the impact in hospitals of noise from 'clinical sources' (for example, monitors, infusion pumps and other equipment)' has been investigated. Cunha and Silva (2015: 246) concluded that noise can have a significant detrimental physiological and psychological impact upon hospital patients and that noise levels in hospitals should be lowered.

The risk of not gaining rest or relaxation to parents' health and wellbeing and ability to provide safe care for their child is clear. Whilst there is a plethora of literature about sleep disruption in parents of children who are technology dependent (Lindahl and Lindblad, 2011; Woodgate et al., 2015; Page et al., 2020; Spratling and Lee, 2020), there is a paucity of current literature about how sleep disruption impacts children who are technology-dependent and their siblings. Disruption to sleep quality and quantity increases the risk of morbidity and mortality (World Health Organization Europe, 2009) and impacts upon the body's ability to regenerate. Sleep is important for children and young people's social, physical and mental health and wellbeing. Sleep disruption (Sadeh, Raviv and Gruber, 2000) and deprivation in children and young people is known to have a negative impact upon their learning, behaviour and mental health (Schotland and Sockrider, 2017; Fuligni et al., 2018) and social outcomes (Matricciani et al., 2013). Sleep deprivation is known to increase the risk of medical conditions such as diabetes, obesity and hypertension (Matricciani et al., 2013; Schotland and Sockrider, 2017).

One way to improve the regeneration and at-easeness aspects of at-homeness for the families would be to give parents control over the tone, volume or sounds of non-life-saving technology such as the feeding pump as this was the type of technology that annoyed parents the most. The United States Environmental Protection Agency and the International Noise Council made a recommendation in 1974 that the noise levels in hospital acute care areas (so comparable with contemporary home care environments for children with complex health care needs) should not exceed '45 dB during the day… and 20 dB (a soft whisper) at night' (Schweitzer, Gilpin and Frampton, 2004: 74). Cunha and Silva (2015: 246) suggest that all health and social care professionals, including clinical psychologists, and practitioners should be aware of the detrimental physiological and psychological impacts of noise. This study suggests that at-homeness could be improved by lowering the noise levels of technology in the home thus supporting regeneration and at-easeness and the health and wellbeing of all family members.

5.3.4 Summary (Regeneration and At-Easeness)

This section of the chapter has discussed how the constant presence of carers in the home, parents always being on call for their child, and the intrusiveness of the sounds of the technology and equipment impacted upon the at-easeness and regeneration aspects of at-homeness for the families. Although the impact of the constant presence of carers within the family home has been previously reported, this study is the first to discuss how the presence of carers and being constantly on-call impacts upon the at-easeness and regeneration aspects of at-homeness. Previous research has paid attention to the sound levels of technology in hospitals, particularly in intensive care units, but this is the first study to describe the impact of these sounds on the ability of family members who have a child who is technology-dependent to rest or relax in their home. The impact upon all aspects of health and wellbeing of never being able to escape from the sounds of the technology, even when trying to sleep, was profound for the family members who took part in this study. Seamon (1979: 82-83) notes that 'without a place for regeneration, a person's life almost surely disintegrates'; this disintegration was evident in the accounts of the exhausted parents in this study.

5.4 Home is Accessible but Other Homes are Not (Rootedness)

Seamon (1979a: 79, 1979b) states that 'rootedness' is about the home being 'a physical centre for departure and return'. Rootedness is also about the home being a place where the habits and routines that are formed there save a person mental energy because of enabling them to move around in the home and find objects within it without thinking. Rootedness is unconscious (Buttimer, 1980; Tuan, 1980; Williams, 2002; Seamon and Sowers, 2008) and is only brought to consciousness when the person's meaning of home is threatened (Buttimer,

1980). Technology both supported and challenged the family members' rootedness by enabling families to live at home together (presented in the emotional warmth aspect of at-homeness because this positive aspect of living with technology for rootedness and emotional warmth was so entwined), but also creating barriers for leaving the home and accessing the homes of other people.

For the families in this study, the technology enabled them to leave the home, which was an enjoyable, beneficial experience. As reported in other studies with children who require home mechanical ventilation (Earle et al., 2006; Israelsson-Skogsberg et al., 2018), the two technology-dependent young people who took part in this study were more focused on their belongings, activities and friends than their technology and how this impacted upon their life and home. These young people both loved going out and having the mobilisation (power chairs) technology as this gave them the independence to self-mobilise in their favourite places to meet new people and have new experiences. They both loved their communication technology (eye gaze computer/iPad) as they could stay in touch with their family and friends without relying upon other people. As reported by the Foundation for People with Learning Disabilities (2014), mobilisation and communication technologies enable children to participate in life and to feel less isolated. Israelsson-Skogsberg et al. (2018) note that these types of technology are vital for cognitively able children to live a more active and social life. One of the children in this study reported feeling very depressed and isolated when her mobilisation and communication technology broke down, resonating with findings by Carnevale et al. (2006) and Earle et al. (2006).

However, whilst the mobilisation technology created the potential for the children and their families to leave the house, requiring adaptations and the other types of technology, and having such complex care needs, created barriers to leaving the home. Mothers found this emotionally and psychologically challenging. There were three main challenges to individual family members and the family as a unit leaving their home and accessing the homes of their friends and extended family members: 1) the lives of the family members revolved around their child's routines of care, 2) other people's homes are inaccessible for their child, and 3) one parent always has to remain at home because their child cannot be left alone with carers. Each of these challenges to the home being 'a physical centre for departure' will be discussed in this section of the chapter (Seamon, 1979a: 79).

5.4.1 The lives of the family members revolved around their child's routines of care

The first challenge to rootedness was that parents had to adhere to strict schedules of care for their child and had to plan their lives carefully to fit in around their child's health and technological needs. This was a finding that has been identified in other studies with families who have children who rely upon technology or who have special health care needs (Lindahl and Lindblad, 2011; Nygård and Clancy, 2018; Boss et al., 2020). Despite the move from the medical model of disability to a social model of disability over the past three decades, it was evident that the children's illnesses disrupted the family members' feelings of freedom and control over their lives, as found in other work (Lindberg et al., 2017; Israelsson-Skogsberg et al., 2018). As Gadamer (1996) theorised, not feeling involved with everyday life and friends resulted in feelings of exclusion from life.

The children's care routines often restricted or prevented the family and members of the family from going out. Mothers reported that they could not spontaneously carry out routine tasks such as shopping for groceries because, like other studies from across two decades with children who are technology-dependent (Israelsson-Skogsberg et al., 2018), and their siblings (Barr and McLeod, 2010; Woodgate et al., 2016) or parents (Diehl, Moffitt and Wade, 1991; Rehm and Bradley, 2005a; Hobson and Noyes, 2011; Mitchell et al., 2016; Toly et al., 2019; Boss et al., 2020) had found, it took great organisation and effort to go out. As their child grew, families found it increasingly difficult to leave the house. This resonates with other work which has described how parents of children with complex needs can find going out physically challenging and requires constant vigilance to keep their child safe (Nicholl, 2015; Lindahl and Kirk, 2018; Page et al., 2020). As reported by other literature, the child's health and technological needs created barriers to family activities and social activities and also had a detrimental impact for siblings' social wellbeing as the technology-dependent child was always the focus of their parents attention (Carnevale et al., 2006; Barr and McLeod, 2010; Toly et al., 2017).

5.4.2 Other people's houses are inaccessible for their child

A key challenge for the families, and an original finding, was the difficulty that they had in accessing the homes of their friends and extended family members with their technology-dependent child. Parents found being confined and constrained by this barrier to socialisation exceptionally hard to live with. Rasmussen and Edvardsson's (2007: 126-7) study with participants living in a hospice also found that remaining in touch with family and friends was an important aspect for at-homeness. Even when the families could navigate their child's time-consuming, unpredictable, complex and life-threatening care needs, they found it difficult to

maintain connections with friends and extended family members. This was a finding that has been reported by other researchers who have conducted studies with families of children who were living with technology, such as ventilators, at home (O'Brien, 2001; Dybwik et al., 2011; Nicholl, 2015; González et al., 2017).

Sine (2015: 7) notes that 'private homes, unlike hospitals, are not designed to be "disability friendly" or to meet architectural requirements for access'. Issues arose with steps, narrowness of doors, and limited internal space, even in new build homes that had wider doorways and lower light switches and electrical sockets. These restrictions meant that extremely large and heavy wheelchairs could not gain access, be manoeuvred, or fit inside the houses of their friends and family. Parents and an older sibling also had difficulty in transporting and carrying the other types of heavy and unwieldly technology into other people's homes. Other studies have reported the difficulties in transporting heavy and burdensome technology and equipment outside of the home (Kirk and Glendinning, 2004; Nicholl, 2015; Toly et al., 2019).

This study adds depth to the evidence about the architectural and social barriers that families continue to experience in the present day (Sine, 2015), which impact upon rootedness (Seamon, 1979b) and can lead to feelings of isolation and loneliness, as reported by Together for Short Lives et al. (2018), and represent why technology needs to be 'small … and easy to carry' (Israelsson-Skogsberg et al., 2018: 12).

5.4.3 Some mothers felt like prisoners in their home

Ideally home is 'a physical centre for departure and return' (Seamon, 1979a: 79), a 'place to long for' when away (Lindahl et al., 2006: 897), and a place of relief (Årestedt et al., 2016). However, like other research with parents of children with complex needs (Collins *et al.*, 2016; Wilkinson, Bray, *et al.*, 2020), several mothers in this study found that home was a site that they could not depart from. As stated by Lindahl and Kirk (2018:9), 'leaving the home… [was] no longer a taken-for-granted event' for mothers. This was a finding that was only applicable to the mothers in this study because they were the parent who had left employment or reduced their working hours to become their child's primary caregiver. Mothers in studies of similar populations had likewise been found to leave employment or to adjust or reduce working hours (González et al., 2017; Israelsson-Skogsberg et al., 2018; Camara and Callum, 2020), possibly because people tend to expect mothers to give up their career to take full responsibility for their child's care, even though this care is 'too much for one person to handle' (Boss et al., 2020: 181). There were two main reasons why rootedness was impacted for some mothers: The first reason was the lack of alternative care environments or professionals with

appropriate medical and technological skills to meet their child's needs. The second reason was because families could not leave their child on their own with paid carers because carers were not professionally qualified, and thus not officially allowed, to give their child medication or deal with any medical or technological emergencies.

For some of the mothers in this study, not being able to leave their home or access other people's homes with their child made their home feel like 'a prison, rather than a place of absolute freedom' (Mallett, 2004: 72). The conflicting emotions that some mothers felt about their home impacted upon their ability to feel rooted to it. This was a finding that aligns with that of Manzo (2003: 52), who reports that 'those who experience the residence as a trap' can feel a sense of alienation from their home. Home was no longer 'a secure point from which to look out on the world' (Relph, 1976: 38) for these mothers because they could seldom escape from it into the outside world. This resulted in them feeling isolated from their extended family members and secluded from their community, findings that have been reported previously in studies with families who have children who rely upon technology (González et al., 2017; Toly, Blanchette and Musil, 2019; Chiang and Amin, 2020). It was evident that some mothers felt like they had lost their identity because of feeling like a prisoner in their home. Like parents in previous studies (Carnevale et al., 2006; Dybwik et al., 2011; Hobson and Noyes, 2011), some mothers implied that they were living only to provide care for their child. As found in other studies with parents of medically complex children (Lindahl and Kirk, 2018; Currie and Szabo, 2019; Boss *et al.*, 2020; Wilkinson, Bray, *et al.*, 2020), these mothers had lost a sense of who they were.

The need for respite for parents who have children with complex health care needs who require medical technology is emphasised in literature (Toly et al., 2017, 2019; Dunbar, Carter and Brown, 2019; Sobotka et al., 2019, 2020). There is also evidence that siblings need support, and often their needs have to come second to their technology-dependent brother or sister (Lindahl and Lindblad, 2011; Toly et al., 2019; Page et al., 2020). Siblings are often not identified as young carers (Rainbow Trust Children's Charity, 2018) and they need respite from these responsibilities. Parents said that they must have support if they are to survive and remain physically, mentally and emotionally well enough to continue providing high quality, emotionally warm and responsive care for all their children. That some families could not expect (Collins et al., 2016) or did not have physical or emotional support from extended family members and friends (Paddeu et al., 2015; Mitchell et al., 2016; González et al., 2017) or receive any formal respite inside or outside of their home is concerning and resonates with other literature (Sobotka et al., 2019; Toly et al., 2019; Brenner et al., 2020). Whiting (2014)

reports respite to be the greatest area of unmet need for families of children who have complex health care needs.

Home can be a place of safety and security, regeneration, rootedness and warmth, but only if all family members have the opportunity to have a break from caring and gain the rest that they need, as well as being able to leave their home, and it is for this reason that families require regular respite support from nurses who can be left on their own with the child.

5.4.4 Summary (Rootedness)

The findings of this study demonstrate how living with technology both supported and challenged the rootedness aspect of at-homeness for the family members. The adaptations, technologies, equipment and consumables supported rootedness by enabling the family to care for their child at home and keeping the family together at home. The adaptations and mobilisation and respiratory technologies enabled the homes of the families to be, to a certain extent, 'a physical centre for departure and return', therefore supporting rootedness.

However, there were barriers to rootedness. Although the children loved going out, families encountered challenges to leaving their home due to their lives revolving around their child's medical and technological care, and sometimes around the size and weight of the technology. These barriers to accessing and being part of their community resulted in the home feeling like a prison, which, for some mothers led to feelings of frustration, isolation and loneliness. These feelings then had a detrimental impact upon how mothers felt about their home and their feelings of at-homeness. Challenges to re-establishing rootedness following alterations to their home or the introduction of technology resulted in a sense of loss of control over their home (demonstrating how appropriation and rootedness overlap) causing the home to no longer feel like a place of comfort in times of stress and uncertainty.

Families require regular high-quality nursing support, as well as carer support, to be able to leave their home, to maintain relationships with their friends and family members, and to remain physically, mentally and emotionally well enough to continue caring for their child at home. This support would not only prevent parents from potentially becoming too exhausted to function and to provide safe, high quality care for their child (Paddeu et al., 2015; Spratling and Lee, 2020), which could result in the hospitalisation of their child (Sobotka et al., 2020), but would support their psychological resources to maintain 'a healthy, balanced person-environment relationship' (Young et al., 2018: 105). Their home could then have the potential to be a place of regeneration, rootedness and emotional warmth (Seamon, 1979).

5.5 Home Looks and Feels Different (Physical Warmth) but is a Place of Love, Care and Support in Action (Emotional Warmth)

When Seamon (1979a:84) refers to the 'warmth' aspect of at-homeness, he is referring to both the physical and the emotional atmosphere of the home. He states that a physically warm home is a home that is cared for – a place that is kept clean and tidy and in a good state of repair (Seamon, 1979a). A home that is emotionally warm is one that 'fosters an atmosphere of … concern and support', 'interpersonal harmony' and a place that feels 'comfortable, [cosy] and safe' (Seamon, 1979a: 84). The impact of living with technology upon the home and life at home for the physical and emotional warmth aspects of at-homeness (Seamon, 1979a) will now be discussed.

5.5.1 Home looks and feels clinical and cluttered (physical warmth of home)

Seamon (1979a: 85) states that 'care is associated with places of warmth: the person feels concern for the home and keeps it ordered and in good repair'. Lewicka (2011: 225) states that part of the reason why 'homeowners are more attached to their dwellings… is the emotional and financial investment [that they make] in buying and decorating the dwelling'. However, aspects of warmth were not under the control of the parents in this study.

The families in this study were all homeowners and had all lived in their homes for between five and 20 years. They had, as such, made a long-term emotional and financial investment in their home and were invested in it, as seen in other work (Seamon, 1979a, 1979b; Lewicka, 2011). The families had the long-standing habituation in their home that Tuan (1980) and Williams (2002) assert is necessary for familiarity and rootedness, and that Lewicka (2011), Hay (1998) and Brown et al. (2003) state is a consistent predictor of place attachment (the emotional bond between a person and a place).

Despite living in their home for a long period of time, parents felt that their home looking like a hospital and a storage facility had a detrimental impact upon the look and feel of their home (physical warmth). The finding that technology can impact upon the atmosphere of and space within the home has emerged in other studies conducted on families who have technology-dependent children (Carter et al., 2018; Lindahl and Kirk, 2018; Wilkinson, Bray, et al., 2020) and fills the gap in knowledge about the ways in which home can disappoint, aggravate, and confine people as much as the positive impacts that it can have (Moore, 2000).

Home was a place of belongingness and togetherness with both happy and sad memories of everyday living, as seen in other work (Lindahl, Sandman and Rasmussen, 2003; Barry et al., 2018). Negative memories of the adaptation experiences contrasted with happy memories

and experiences of being able to enhance their child's health and wellbeing and quality of life. This created warmth despite feeling some loss of control and rootedness. This dedication to giving their child the most opportunities and experiences to ensure that they had a good life, even if it was likely to be short, resonated with other literature (Dybwik et al., 2011; Woodgate et al., 2015; Carter, 2016). The mobilisation technology enabled their child to be fully involved in the family space and to access their community to be able to make these memories. The older sibling talked about having two homes – the home in the city where she now lived and 'home, home' being the place where her family lives and where she grew up. This was a finding that demonstrates the long-term impact of how happy memories in a place can contribute to place attachment (Zingmark et al.,1995) and feelings of nostalgia (Massey, 1994; Francis, 2018), and that home, despite where a person is now living, can be the place where a person grew up (The Home Project, 2015; Moodscope, 2017; Francis, 2018).

Although Seamon (2017: 102) states that quality of life is 'directly tied' to how a person cares for and attends to the physical warmth (the look) of their place, some families paid little attention to how living with technology had altered how their home looked once they had become familiar with it. Indeed, as also reported by Mandleco (2013), some mothers had forgotten to photograph some types of technology and equipment. This could have been because items such as the van, ramp and wheelchair were outside the house at the time of their interview, or were not considered as medical equipment, or because the children and their technology and the family had grown together and it was so embedded in daily routine that they did not notice how it impacted upon the physical warmth of their homes anymore. However, some families were less happy about the physical warmth of their homes despite attempts to create a physically attractive home by hiding and disguising the technology, equipment and consumables as best they could. Some mothers said that being constantly vigilant to their child's needs meant that they could not attend to non-essential household tasks such as decorating, or sorting and clearing out unwanted items to keep their home as ordered as they would have liked.

The ways in which the adaptations, technology, equipment and consumables supported the emotional warmth aspect of at-homeness (Seamon, 1979a, 1979b) for the families will now be discussed. Some aspects of rootedness will be included in the emotional warmth section because rootedness and emotional warmth are entwined. Rootedness and emotional warmth for the families were mainly about keeping their family together and having their child at home with them in a loving, safe, comfortable and stimulating environment where they could meet their child's health and development needs themselves. The adaptations, technology, equipment and consumables enabled families to live at home together. The routines that had

a detrimental impact upon the rootedness aspect of at-homeness had a positive impact upon the emotional warmth aspect because they made the family members feel more comfortable, safe and secure in the familiar environment of their home.

5.5.2 Home is the best place of care for their child because it is a place of love, care and support in action (emotional warmth of the home)

Although homes can also be places of abuse, neglect and fear (Manzo, 2003; Mallett, 2004), the homes of the families in this study felt rich in warmth because they had the 'atmosphere of friendliness, concern and support' that Seamon (1979a: 84) suggests is necessary for an emotionally warm home. Family members extended friendliness towards me as a researcher and were supportive of this study. Like the findings of other studies, care and compassion (Lindahl and Lindblad, 2013), support (Schweitzer, Gilpin and Frampton, 2004) and love was extended towards their child/ren, giving an insight into how the homes of the families in this study were emotionally warm places. Providing their child with security, stability, physical and emotional affection was particularly important to the families. This resonates with what Seamon (1979a) means when he talks about the emotional warmth aspect of at-homeness.

The finding about families wanting their home to be a safe, comfortable (The Health Foundation, 2017), loving and stimulating environment where they could care for their child themselves (Bourke-Taylor, Cotter and Stephan, 2014; de Lima, de Paulo and Higarashi, 2015; Israelsson-Skogsberg et al., 2018), and keep their family intact by keeping their child out of hospital (Castor et al., 2018; Sobotka et al., 2018, 2020) has been reported elsewhere. However, a new finding was that having the adaptations, technology and equipment at home enabled the families to stay together as a family, and this was what rootedness and warmth was about for them.

It was clear that the families, like those in previous studies, loved and were devoted to their child and would fight for what was best for them (Currie and Szabo, 2019; Toly et al., 2019; Boss et al., 2020; Spratling and Lee, 2020), demonstrating the action behind their words of love. The children were seen first as a person by their family members, rather than being overshadowed by their illness or disability. Similar to the findings of other studies, parents fought to get others to value their child as an important person (Öhlén et al., 2014; Saarnio et al., 2017; Toly et al., 2019; Boss et al., 2020). Being recognised as a person is reported by Saarnio et al. (2017) and Rasmussen and Edvardsson (2007) as being an important aspect for feelings of at-homeness in older people or those in receipt of palliative care.

Like parents in other studies, parents wanted to be good parents to their child by meeting all their needs, as well as giving them positive experiences (Carnevale et al., 2006; Woodgate et al., 2015; Currie and Szabo, 2019; Wilkinson, Bray, et al., 2020), at the expense of their own health and wellbeing (Woodgate et al., 2015; Collins et al., 2016; Wilkinson, Bray, et al., 2020). Parents were dedicated to becoming experts in providing the best medical, technological, personal and emotional care for their child, as seen in other studies (Boss et al., 2020; Camara and Callum, 2020; Page et al., 2020; Spratling and Lee, 2020). As found before (Woodgate et al., 2016; Toly et al., 2017; Castor et al., 2018), the siblings who took part in this study were eager to be involved in their brother or sister's care to support their parent(s).

The parents all wanted to care for their child at home because they believed that their home was the best place to care for their child and to support their physical, emotional, psychological and social development. This finding supports those of other studies from around the world with families who have children who are dependent upon technology (Wang and Barnard, 2004; Cockett, 2012; Alsaleh et al., 2014; González et al., 2017) or who have complex health conditions (Department of Health, 2011; Castor et al., 2018). Parents suspected that their child would not survive in residential care environments because of the lack of staff who had the required medical and technological skills. This was a finding that echoed those of previous studies with families of technology-dependent children and the professionals who were in contact with these families (Kirk and Glendinning, 2004; Mitchell et al., 2016; Boss et al., 2020). As found by Spratling and Lee (2020), parents believed that home was the place where their child was known best and, like other study findings (Kirk and Glendinning, 2004; Kirk, Glendinning and Callery, 2005; Lindahl and Lindblad, 2011), could receive the necessary medical, technological, social, emotional and developmental care and attention without delay.

Relph (1976) theorises that knowing and being known in a place contributes to the rootedness aspect of at-homeness, showing how rootedness and warmth are entwined. Lindahl and Lindblad (2011: 250) state that the 'body functions [of technology-dependent children] were best maintained in the home', but their minds were better challenged outside of the home. However, parents and the older sibling in this study emphasised how they could better anticipate and be responsive to their child's needs and that their child's mind was stimulated by being at home with their family. They said that the social interaction and activities that occupied their child's mind were important for their child's health and development and quality of life. Playing on their bespoke play and leisure equipment and being supported with their augmentative and alternative communication devices meant that children could be connected and gain the most experiences at home and in their community. Ensuring that their child had

experiences that were good for their development and that supported them to lead a fulfilling life was a priority for parents and siblings in this study.

Similar to Castor et al.'s (2018) findings with children, siblings and parents in Sweden, and Page et al.'s (2020) findings with parents of children with complex health care needs in the UK, everyday life is normalised and family life can be strengthened by home-based, rather than hospital-based care for their sick child. Regardless of their sense of rootedness, parents found it easier to care for their child in their home than in any other environment, especially once the adaptations, technology and equipment were integrated into the physicality of their home and their routines. For the most part, parents could operate on automatic pilot, performing medical and technological procedures for their child that had become part of their routine and which were taken-for-granted and everyday tasks, as well as their other parenting roles. Like the elderly women in Cristoforetti et al.'s (2011: 228) study about at-homeness, parents created 'spot locations' for the technology and equipment. Despite their child's needs being complex and unpredictable, keeping the technology and equipment in *'its own little special place'* enhanced coping in parents. Both Seamon (1979) and Buttimer (1980) say that familiarity with the environment and the objects within that environment is an important aspect of rootedness, and for the families in this study, it also enhanced warmth.

Being able to be authentic and experience love is 'often attributed to a sense of belonging to a family' (Lawson, 2018: 420). Familiarity and feeling comfortable with the people inside their home was as important to the family members as familiarity with their home, supporting suggestions by Tuan (1980) and Relph (1976) that the home being a place of comfort and relaxation are also important factors for the rootedness, (warmth, and at-easeness) aspects of at-homeness.

5.5.2.1 Home is a place of structure and family routines

Parents wanted their child to be at home rather than in hospital, whenever possible, because of the impact that their child's hospitalisation had upon their child's development, the mental and emotional wellbeing of their other children, and the functioning of their family. Whilst literature from Canada reports that children who are technology-dependent experience have frequent unplanned hospitalisations (Breneol, Goldberg and Watson, 2019), the findings from this study show that having the respiratory technologies at home prevented the children from being hospitalised, or significantly reduced the length of time that the children were in hospital for, with benefits for both the family and the NHS. This finding aligned with those of Boss et

al. (2020) who found that the incidence of hospitalisation is reduced as a result of the parents providing vigilant care and having technology at home.

The mobilisation technologies (tracking and hoists, lifts and wheelchairs) became some of the favourite types of technology for all family members because they enabled the home to become what Relph (1976: 38) describes as a ‘field of care’; a place where children could be cared for whilst being involved in family routines and activities, which are aspects that contribute to both emotional warmth and rootedness. These technologies enabled their child to be fully involved in the family space rather than being confined to bed.

Having their child at home supported the rootedness and warmth aspects of at-homeness (Seamon, 1979b), with benefits for the family as a unit and as individuals. The family were together in the home space (rather than their child and at least one parent being in hospital), thus the negative impacts upon the health and wellbeing of all their children and the functioning of their family were reduced. Like Castor et al.'s (2018) findings, families were not split up. They could maintain their usual routines and could save valuable time and energy by not having to go to the hospital.

There is little comparative data on the costs related to caring for a technology-dependent child in the home or in hospital. The data that exists is somewhat dated but notes that there are potential cost savings for the NHS of 78% when technology-dependent children are cared for at home because the annual relative cost of caring for a medically stable child at home (£104,352 per annum) is less than a quarter than that of hospital care (£482,259 per annum) (Section 1.4) (Noyes, Godfrey and Beecham, 2006). This is an important consideration given that the prevalence of this population of babies, children and young people has almost trebled in the UK between 2001 and 2017 (Together for Short Lives, 2020b) and an increasing number of these children ‘have a hospital stay of greater than 28 days each year’ (Fraser et al., 2020: 10), although care must be taken not to shift the costs of care onto families (de Banate et al., 2019: 575) as caregiving activities within the home are often invisible and ignored (Wang and Barnard, 2004; Age UK, 2010; Rainbow Trust Children’s Charity, 2018).

Whilst the routines that their child’s health and technological needs imposed upon their family’s lives had a detrimental impact upon the departure from home aspect of rootedness, these same routines had a positive impact for emotional warmth. This was a new finding. Like O’Brien (2001) had found, the children’s medical and technological needs brought uncertainty and unpredictability into the lives of the families but, by caring for their child at home, the families could adopt a routine that suited what Rasmussen and Edvardsson (2007: 127) would

call their ‘own rhythm’ when they were at home. Other researchers have reported about families being able to initiate routines of care that suit and strengthen the functioning of their family when they are at home (Lindahl and Lindblad, 2011; Woodgate et al., 2015; Toly et al., 2017; Castor et al., 2018).

Resonating with the findings of other studies (Gillis, 2002; Moodscope, 2017), parents said that even though life is hard and stressful, when they are in the familiar environment of their own home, with their own familiar objects around them, their focus is more upon ordinary everydayness and they can organise their time more effectively and adapt their routines of care to suit the functioning of their family (Carnevale et al., 2006; Moore et al., 2010; Vickers and Chrastek, 2012). This helped them to adapt and cope. Having their child in the shared areas of the home meant that parents could also attend to their other children’s needs, and like the findings of Castor et al.'s (2018: 227) study, ‘family members could maintain their usual social activities and relations’. Similar to some of the mothers in Toly et al'.s study (Toly, Musil and Carl, 2012b, 2012a; Toly et al., 2017, 2019; Toly, Blanchette and Musil, 2019), this structure and routine was important for families and are the aspects of rootedness that Seamon (1979b), Tuan (1980) and Relph (1976) suggest are important for feelings of safety, security and rootedness to the home. Other studies have reported that having routines and feeling safe are beneficial for family relationships (Saarnio et al., 2017: 43), the family members’ wellbeing (Årestedt et al., 2016) and the children’s health, wellbeing and developmental needs (Bourke-Taylor, Cotter and Stephan, 2014; de Lima, de Paulo and Higarashi, 2015; González et al., 2017).

5.5.2.2 Home as a place of safety

Having a *‘nice, safe environment’* was a requisite to feeling at-home for the family members in this study. This was a finding that replicated those of other studies that have researched at-homeness in family homes (Zingmark, Norberg and Sandman, 1995; Moore et al., 2010; Owen and McCann, 2018) and therapeutic communities[20] (Lawson, 2018: 413), such as residential care homes, nursing homes (Öhlén et al., 2014; Saarnio et al., 2017), and adult (Öhlén et al., 2014) and child hospice environments (Dunbar, Carter and Brown, 2019; Dunbar and Carter, 2020).

[20] Therapeutic communities are ‘any place where people live together … because they can no longer manage to live in their usual family or social environment’ (Lawson, 2018: 413).

The findings of this study presented across all three themes and all four sections of the discussion have demonstrated that families can meet the needs of their child at home and when accessing their community because they 'know' their child, are able to anticipate and be responsive to their needs, have the necessary medical and technological competence and expertise, and have the necessary adaptations, technology and equipment. However, these same findings demonstrate how their child's need for technology and equipment also created challenges for feelings of safety and thus, impacted upon all five aspects of at-homeness.

Some of the challenges for feelings of safety were to do with the physical structure of and use of space within their home, whilst others were to do with the physical, psychological and emotional responses to living with technology. Parents feelings of safety were impacted by changes to the physical structure of and use of spaces within the home and the lack of control that they had over this. Issues such as adaptations that would not have been accessible or big enough for their child, or their child's bedroom being located downstairs, impacted upon parents' feelings of safety because of not always being near their child. These were findings that align with those of Malone (2003: 2317), who reports that 'spatial-structural' changes in hospitals can create distal rather than proximal relationships with patients for nurses.

Parents' and siblings' feelings of safety were also impacted by living in a home where the technology is so painfully visible and audible, as this caused psychological and emotional responses for parents and siblings, reminding them of the times that they had resuscitated their child and triggering anxiety about the fragility of their child's life, a finding that is reported by other researchers (Nicholl et al., 2013; Toly et al., 2017). Similar to the findings of other studies, parents could not bear to think about life without their child (Carnevale et al., 2006; Moore et al., 2010; Alsaleh et al., 2014). However, like other researchers had found, the threat of being without their child caused families to re-evaluate what was important in life for them and to make the most of their time as a family (Dybwik et al., 2011; Woodgate et al., 2015; Nishigaki et al., 2016; Toly et al., 2019).

One mother in this study used the metaphor of her home being her *'safe haven',* aligning with Lawson's (2018: 420) findings that some family members feel a 'sense of safety in just being in the house'. The above challenges for feelings of safety, however, illustrate why those involved in the adaptation and provision of technology and equipment processes must consider the children and their family's current and future accessibility and safety needs, and as mentioned earlier, must take into account the impact of the sounds of the technology for feelings of safety. The needs of all family members must be met if they are to achieve all five aspects of at-homeness (Seamon, 1979b).

5.5.2.3 Home feels wrong and family feels incomplete without their child

The findings from this study reveal that the homes of the families did not have to be 'ordered… tidy and in good repair' to be warm; this is in contradiction with Seamon's (1979a: 84) propositions on the physical and emotional warmth aspects of at-homeness. Although Lawson (2018: 419) suggests that a house can take 'on the character of a family', the homes of the families in this study were to a degree dominated by the character of their child's adaptations, technology, equipment and consumables. Although parents said that their child's needs had to be prioritised before the needs of other family members, like the findings of Toly et al.'s (2019: 5) study, they were aware that this was typical of most families and that families who do not have technology-dependent children make 'sacrifices to accommodate familial needs all the time'. Furthermore, parents believed that the negative impacts on how their home looked and functioned (physical warmth) (Seamon, 1979a) were worth it for their child to live at home as part of their family and community. Like the findings of other studies with families who have a child with complex health care needs (Woodgate et al., 2015; Carter et al., 2017, 2018; González et al., 2017), parents also believed that the negative impacts for the health and wellbeing and quality of life for all the family members and the functioning of the family were worth it for their child to live at home. Their family felt incomplete, and their home felt wrong without their child. As found in other studies, home is where the heart is, where loved ones or family are (The Home Project, 2015; Moodscope, 2017; Francis, 2018). Indeed, the families' lives were more complete, and as reported by Camara and Callum (2020: 404), it appeared that the families' lives were 'enriched and enhanced by having [their] technology-dependent child at home'.

Some mothers described the atmosphere of their homes as feeling totally different when their child was in respite. They did not like their home being in darkness and seeing their child's technology, equipment and consumables lying around unused, because this foreshadowed the permanent absence of their child. This finding demonstrates that, for the families in this study, attachment to place (home) was about their child being in that place. This finding is in contrast to Lewicka's (2011) findings that place attachment for some people is about the physical assets of that place, such as the place looking nice or being a place of recreation, rest, or physical stimulation. Black, Holditch-Davis and Miles (2009) also found that most parents prefer to be at home because home is the place that they can best get to know their child.

As in other studies, although the sense of at-homeness was altered, home for the families was still a place of everyday living (Buttimer, 1980; Dunbar, Carter and Brown, 2019) and belonging

(Moore et al., 2010; Lindahl and Kirk, 2018), not only because parents had parental responsibility for their child(ren), but also because of the love and emotional connection between the family members. Similar to Zingmark et al.'s (1995: 51) findings that 'caring and being cared for, and belonging … [are] essential to the experience of being at home', being able to care for, love, comfort and support their child at home, in the place where family members felt like they belonged was a central feature of the rootedness and emotional warmth aspects of at-homeness that symbolised home for the families. These findings echo those of Moore (2000: 213) about the importance 'of interrelated qualities of people, environment and time' for feelings of at-homeness, and demonstrate the importance of examining home 'as a holistic entity'.

5.5.3 Summary (Physical and Emotional Warmth)

This section of the discussion has made explicit that Seamon's (1979a) warmth aspect of at-homeness consists of physical and emotional warmth. The family members who took part in this study believed that struggling with the detrimental impacts on the look and functioning (physical warmth) of their homes, as well as their own health and wellbeing and quality of life, were worth it for their child to live and be cared for in an emotionally warm, safe, supportive and stimulating environment at the centre of their family. The adaptations, technology, equipment and consumables enabled the family to live at home together, supporting the emotional warmth and rootedness aspects of at-homeness. The emotional warmth aspect of at-homeness for the families, like rootedness, had more to do with their emotional and psychological attachment to their home and their family than the practical impact of living with the technology, resonating with the saying that home is not a place, it is a feeling. Having their child at home created opportunities for families to give their child the love, attention, social interaction and stimulation that they needed for their health, development and quality of life. The home was a place of belonging and memory making for all family members. Home did not feel like home and their family did not feel complete without their child being at home, clearly showing how entwined the emotional warmth and rootedness aspects of at-homeness are.

5.6 Strengths of the Study

Use of the Vitae Researcher Development Framework (RDF)[21], developed in 2011, has been ongoing throughout this study and has enabled me to identify my strengths and the gaps in my knowledge base, cognitive abilities and creativity (Domain A - Knowledge and intellectual

[21]https://www.vitae.ac.uk/vitae-publications/rdf-related/researcher-development-framework-rdf-vitae.pdf

abilities), personal qualities, self-management and professional and career development (Domain B - Personal effectiveness), professional conduct, research management and finance, funding and resources (Domain C - Research governance and organisation), and working with others, communication and dissemination and engagement and impact (Domain D - Engagement, influence and impact). It also helped me to build on all 12 sub domains and 63 descriptors of the RDF to evidence that I have acquired the knowledge, behaviour and attributes of a professional and successful researcher.

At the beginning of my study most of my personal professional development was centred around identifying and building my research question and skills related to literature searching and quality appraisal skills. I also developed my knowledge base about auto-driven photo-elicitation and the concept of 'home'. I learnt about the importance of using a structured approach, such as PCC (Patient, Concept, Context) (The Joanna Briggs Institute, 2015), for the literature review and study question formulation. I sought the support of an expert librarian to develop my skills in navigating the databases in order to complete a rigorous search of the literature for the literature review.

Although I felt that I had good communication and interpersonal skills, I became aware of my tendency to overwrite and the impact this could have on my work (Domain D of the RDF). The recruitment materials, this thesis and other dissemination materials stand as testimony to how hard I have worked and how hard my supervisory team have worked to support me in developing a more succinct writing technique and the importance of having enough white space on written materials.

The strengths of this study are apparent across the study. Employing the integrative review method (Kirkevold, 1997; Cooper, 1998; Whittemore and Knafl, 2005) allowed me to collect, analyse and combine quantitative, qualitative and mixed method empirical studies and non-experimental studies from fields inside and outside of health in a systematic way to present a comprehensive synthesis of findings. Employing the MMAT quality appraisal method (Pluye et al., 2011) also strengthened the findings of the integrative literature review and adds to our knowledge about the methodological quality of previous studies conducted in this field.

My study is underpinned by a holistic, person-centred and inductive approach and this is a strength for two reasons. Firstly, this approach drove me to develop research materials with family members who have technology-dependent children to increase the accessibility of the study and ensure that the findings and recommendations are relevant for informing the provision of resources and practice. Secondly, this approach enabled me to engage *with*

participants to construct a deep and detailed understanding of their subjective experiences of how medical technology impacts upon the home and life at home.

Another strength of my study is that I engaged with a broader range of family members (children who are technology-dependent and their siblings, mothers, fathers and a grandmother) than is typical in studies like this. Furthermore, family members could choose the method that they were most comfortable with, thus empowering them to contribute in a meaningful way, and consequently enhancing the quality of the data generated and the quality of the findings. My verbal and non-verbal communication skills were another strength of this study. My ability to adapt my communication approach and to use AAC enabled children who would otherwise have been unable to take part in this study to participate. Including the voices of technology-dependent children and their siblings is a strength because, as noted in the integrative review, their voices are often not heard in studies in this field. My PhD research journey has provided me with the opportunity to develop my theoretical knowledge and practical application of thematic analysis (Braun and Clarke, 2006), as well as the practical application of NVivo (QSR International, 2016) and Mendeley.

Throughout my study I have paid attention to the issues of quality, rigour, authenticity and transparency. The rigorous methods used to provide a rich and meaningful account of the data provide evidence that my interpretation of the data is trustworthy.

Furthermore, I have carefully considered how my study and the reporting of it aligns to the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (2018). I am satisfied that the following CASP (2018) quality criteria have been met: There is a clear statement of the objectives of the research, as shown in Section 2.10; A clear rationale for my relativist ontology, interpretivist epistemology, and generic qualitative methodology is provided and is appropriate for addressing the research goal, as shown in Sections 3.2.2-3.2.4; The research design, recruitment strategy, and photo-elicitation and semi-structured interview data collection methods were appropriate to address the research issue, as shown in Sections 3.3.1-3.3.3. The reasons why methods were modified during the study are explained in Section 3.3.5, and why some people did not take part are explained in Section 3.3.6; The imbalance of power in my relationship with participants, and my ethical responsibilities (beneficence, non-maleficence, justice, autonomy, and veracity) towards participants have been considered prior to, throughout and following the study, and although specifically discussed in Sections 3.3.5 and 3.4, are evidenced throughout this thesis; Data analysis was rigorous and evidence of the analysis process is provided in Section 3.5 and Appendices 35-39; There is a clear statement of findings, as shown throughout Chapter 4 and summarised in Section 4.7; The independent,

original contribution to knowledge that this study makes about the impact of medical technology upon the home and life at home for all members of a family who have a child with complex health care needs is valuable for informing the future development and provision of appropriate and effective resources and support that best meet the needs of the whole family (Section 5.8).

5.7 Limitations of the Study

The findings of this study are not representative of and cannot be generalised to all families and family members who have a technology-dependent child. However, qualitative researchers do not seek generalisation of the data (Edirisingha, 2012; Braun and Clarke, 2019). Although ten mothers and a broad range of family members took part in this study, a limitation of this study is the small sample size (n=17 participants). Furthermore, only two children who relied upon technology, two siblings (sisters), two fathers and one grandmother took part. So, although my study engaged a wider population than mothers as primary care givers, which is typical of studies in this field, the range of the participants is not as broad as I had hoped for and the perspectives of brothers, grandfathers and wider family members such as aunts and uncles were not gained. However, this limitation is consistent with the literature included in the integrative review (Appendix 7) which show that it can be difficult to recruit technology-dependent children and young people, their siblings, fathers and wider family members.

Another limitation of this study is that none of the families were new to the medical technology and this limits it's representativeness. They had been living with at least some technology for at least five years and had become accustomed to it. Some family members talked about their family and technology ‘growing together’ and becoming so familiar with it that they sometimes did not notice it. This could mean that the family members in this study paid less attention to the impact of the technology upon their home and life at home than if it had been introduced more recently. Families who were newer to the alterations to their home and technology might have found them to be more disruptive.

Eight families in this study were ‘nuclear’ (Giddens, 2006: 207) mixed gender families and the other two families were single parent families of mothers living with their children. Black, Asian and minority ethnic (BAME) families are not represented in this study. Therefore, the perspectives and experiences of same-sex parent families, families with single fathers, multi-generational families who live together and BAME families might be different to those of the families who took part in this study.

All families in this study owned rather than rented their home. Permanent disfiguration of the home might prevent landlords from agreeing to adaptations and technology, such as tracking and hoists, for those who rent their homes. This study cannot claim to be representative of families who live in social housing or privately rented homes. The perspectives of families who lived in social housing or privately rented homes might be different from families who own their homes.

Some critics might consider a limitation of this study to be that I did not analyse the photographs but used them just as an inductive and empowering stimulus for conversation during the interview and to support my interpretation and analysis of each participant's perceptions and experiences. Although a detailed analysis of the photographs was not possible within the constraints of this study, this did not unduly impact on the quality of the study. However, in future studies I would consider using the description, reflection and formal analysis method (The J. Paul Getty Museum, 2018) for analysing photographs. This method seems to be a logical way of analysing the photographs that is compatible with the philosophical and theoretical underpinnings of studies such as mine. I also acknowledge that photographs do not tell the whole story (Pyle, 2013; Leonard and McKnight, 2015; Papaloukas, Quincey and Williamson, 2017; Williamson, 2018) and that photographs are only one representation of reality (Soaita and McKee, 2020). As such, even if photographs are analysed in future studies, they cannot be expected to capture the complexity of life at home with medical technology.

5.8 Original Contribution to Knowledge and Policy

This study makes four independent, original contributions to knowledge. The first is from the integrative literature review and the second comes from the telephone photo-elicitation study method. The third original contribution to knowledge is that this is the first study involving different members of a family to address the issue of how medical technology impacts upon the home and life at home. The fourth contribution is that, by using Seamon's five concepts of at-homeness as a conceptual framework, my work has extended conceptual understanding of at-homeness in relation to life lived at home for children who are technology-dependent and different members of their families. Each of these contributions to knowledge will now be discussed in more detail.

The integrative literature review is unique because it is the first review to present a comprehensive, quality appraised (Pluye et al., 2011) review of how medical technology impacts the home and life at home for children who are technology-dependent and their family members. Part of its novelty is that the focus of the review was not limited to one type of

medical technology or one medical condition. Moreover, the findings of the integrative review are representative of over 952 parents, 181 families, 79 technology-dependent children or young people, 46 siblings and two grandmothers.

This was the first known study at the time of conducting the study and writing up this thesis to use *telephone* auto-driven photo-elicitation interviews as the main data generation method. However, just before submission of this thesis, a participant-generated photo-elicitation telephone interview study by Soaita and McKee (2020) into the homeliness and housing quality of private tenants was identified. Soaita and McKee (2020) also reported that, bar their own work, participant-generated photo-elicitation had not been mobilised in telephone interviewing before. My contribution to knowledge that telephone auto-driven photo-elicitation interviews are a cost effective method that can be used to generate rich data as effectively as face-to-face photo-elicitation interviews with geographically distanced adult participants support Soaita and McKee's (2020:15) findings.

A third contribution is that this is the first known empirical study to address how the home is altered by technology and how technology impacts upon the sense and meaning of home and life at home for children who are dependent upon technology and their family members. Most other studies fail to consider or engage with different members of a family. This was achieved by adopting a family-based approach and involving individual family members as active participants.

This study is the first to use Seamon's (1979a, 1979b) five concepts of at-homeness (appropriation, at-easeness, regeneration, rootedness and warmth) as a conceptual framework and to extend conceptual understanding of these areas in relation to life lived at home with technology for children who are technology-dependent and different members of their families. In summary, the unique contributions to knowledge include:

- Identification of the differences in experiences between families who were involved in decision making and had control over the adaptations and those who did not.
- The impact on the appropriation aspect of at-homeness that having the child's bedroom downstairs had on the look and functioning of the home (although it is acknowledged that this contribution to knowledge is likely to be UK specific and will not be representative of families who live in single level homes).
- The impact of the lack of control in terms of the location of technology, equipment and consumables and how much space these took up in their home is another aspect to impact upon the appropriation aspect of at-homeness.

- The sensory impact of medical technology in the home space and how these sounds influence the at-easeness and regeneration aspects of at-homeness for the family members.
- The impact of the presence of carers upon the at-easeness and regeneration aspects of at-homeness for the family members.
- The constraints of the architectural and social barriers created challenges for families in accessing the homes of their friends and extended family members with their technology-dependent child.
- Despite the disruption to the home and family life, rootedness and the emotional warmth aspects of at-homeness were achieved through the adaptations, technology, equipment and consumables that enabled the families to be a family.

This new knowledge has been and will continue to be disseminated to families, charities, service planners, commissioners, providers, health and social care professionals and carers, health, education and social care educators, technology manufacturers, builders and architects. This dissemination aims to enhance how equipment and services are planned, developed and delivered to best support the child and family to live at home together for the short life that the child or young person has.

5.9 Recommendations for Future Research, Medical Technology Manufacturers, Policy and Guidance, and Practice

The recommendations for future research, medical technology manufacturers, policy and guidance, and practice will now be presented.

5.9.1 Future Research

The auto-driven photo-elicitation interview method enabled me to work in a collaborative and empowering way with each child or family member (including children and young people who were limited in their communication) to generate rich and meaningful data about the impact of medical technology upon the home and life at home. As the face-to-face and telephone auto-driven photo-elicitation interview method enables participants of all ages and abilities to articulate their views and experiences in a way that aids the researcher's understanding and interpretation, these methods are recommended for use in future qualitative studies. Telephone auto-driven photo-elicitation interviews are a cost-effective method that can be used to generate rich data as effectively as face-to-face photo-elicitation interviews with geographically distanced adult participants. As such, auto-driven photo-elicitation interviews via telephone or video call would be an especially useful data generation method for

researchers who are currently restricted from conducting face-to-face interviews due to COVID-19. However, remote methods require additional skills, experience and sensitivity on the part of the researcher to determine the emotional state of participants to protect their wellbeing.

The following studies could be undertaken to record the rhythm of homes following the process of adaptation (from planning to delivery of final adaptation).

The following prospective longitudinal studies are suggested:

- Comparison of the experiences of families who have Disabled Facilities Grant adaptations to those who do not.
- Addressing the experiences of families who are newer to the adaptations and technology.
- Exploration of the adaptations to the home and how life at home is impacted by technology for families who have technology-dependent children under the age of one year old, as the prevalence of life-limiting conditions is greatest in babies under the age of one.
- Exploration of the experiences of families of technology-dependent children who live in rented accommodation.
- Exploration of the adaptations to the home and how life at home is impacted by technology for technology-dependent adults and their family carers.

In addition, the following study is proposed:

- A mixed methods study to examine the noise levels in the homes of families who have a child who is dependent upon technology, and the impact of this for family members' mental and physical health.

5.9.2 Medical Technology Manufacturers

Medical technology manufacturers should consider adopting co-design principles and should work collaboratively with parents, children, professionals, engineers, designers and manufacturers to:

- Design equipment and technology that is fit for purpose in the home (e.g., aesthetics, sound, size, portability, manoeuvrability) and which supports family's ability to visit family and friends houses together.
- Improve the design of technology and equipment to allow it to serve more than one purpose and reduce the amount of congestion in the home.

- Create technology that takes account of the sound of equipment (alarms, tone, volume, intensity) to allow parents to have some/complete control (as appropriate to specific equipment) to reduce intrusiveness of sound within the home.

5.9.3 Policy and Guidance

Although this is a qualitative study with a small sample size, the findings (which support the findings of other studies) suggest that policy relating to adaptations to homes should:

- Be family-centred and consider the future needs of the child *and* their family members.
- Consider the aesthetics and functionality of the families' homes and be designed by architects who have expertise and experience in the current and future needs of these families.

Policy relating to service provision should:

- Include the provision of respite support by qualified nurses who have experience with children with complex health care needs.

Policy relating to children's wellbeing should:

- Consider that communication technology and leisure and/or play equipment are vital for technology-dependent children's health, wellbeing and development.

5.9.4 Practice

The findings of this study suggest that there is a need to include training in health and social care curricula about how to work with families and technology in the home environment.

All health and social care professionals should:

- Be taught about the impact that technology has upon the home and life at home to improve and enhance their practice and the services and support provided to families.
- Act as advocates for family members and contribute expertise in the acquisition of technology and home adaptation processes.
- Be educated about the detrimental physiological and psychological impacts of the noise of the technology upon families who have a technology-dependent child.

Professionals involved in home adaptations should:

- Make families aware that they can appoint their own contractors to carry out the extension and adaptation work, once their local authority has approved the Disabled Facilities Grant.

- Receive specific training about the needs of families who have a technology-dependent child.
- Work collaboratively (architects, planners, physiotherapists, occupational therapists, social workers) with families to combine their experience and foresight to ensure that adaptations contribute to a sense of at-homeness and are safe, accessible, and functional for all family members.
- Consider the space taken up within the home by consumables, as well as the technology and equipment, and incorporate this into designs.

5.10 Conclusion

The home and feelings of at-homeness were altered by living with technology. Families had little or no choice but to accept the extensions, adaptations and technology that altered the look, sound, feel and function of their home, and they were not always involved in the extension and adaptation processes. Families who had their adaptations fully funded by a Disabled Facilities Grant and who had contractors appointed by their local authority felt a long-lasting loss of control over their home as a result of the negative memories and the emotional and psychological impact of lacking autonomy and control over the adaptations to their home. The intrusion of paid carers and sounds from the technology and always being on call for their child meant that their homes were not always a place of rest, relaxation and regeneration.

Although the adaptations and technology often kept the children out of hospital and supported the families to live at home together, they also created barriers for leaving the home and accessing other people's houses. These barriers to accessing and being part of their community resulted in the home feeling like a prison rather than a place of comfort in times of stress and uncertainty.

However, families were willing to put up with the negative impact that the extensions, adaptations, technologies, equipment and consumables and the presence of carers had upon their home, health and wellbeing and quality of life because they wanted their child to live at home as part of their family. The adaptations, technology, equipment and consumables enabled parents to care for their child at home and enable the families to live at home together.

Despite the challenges, home did not feel like home and family did not feel complete without their child being at home.

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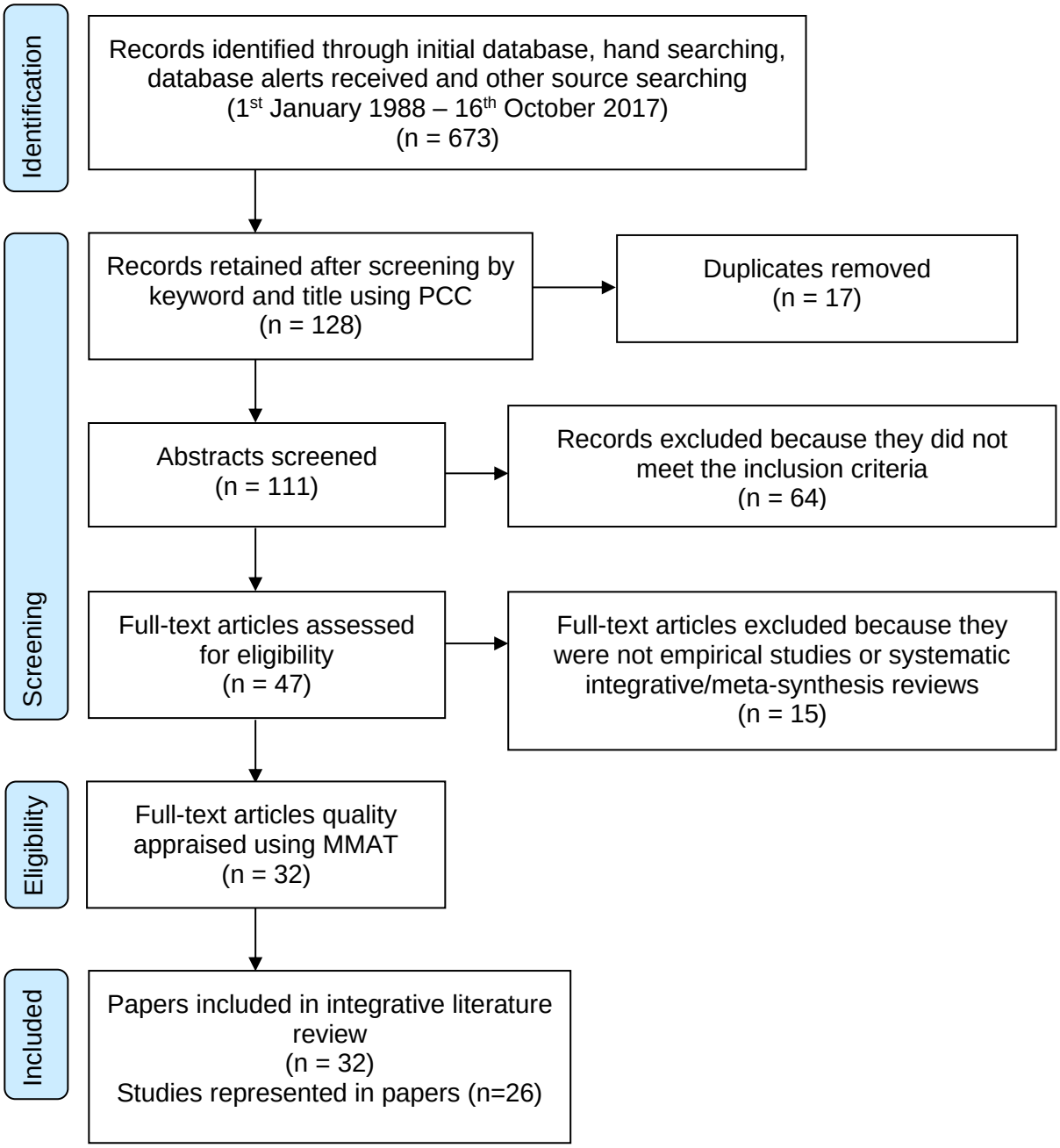
Appendices

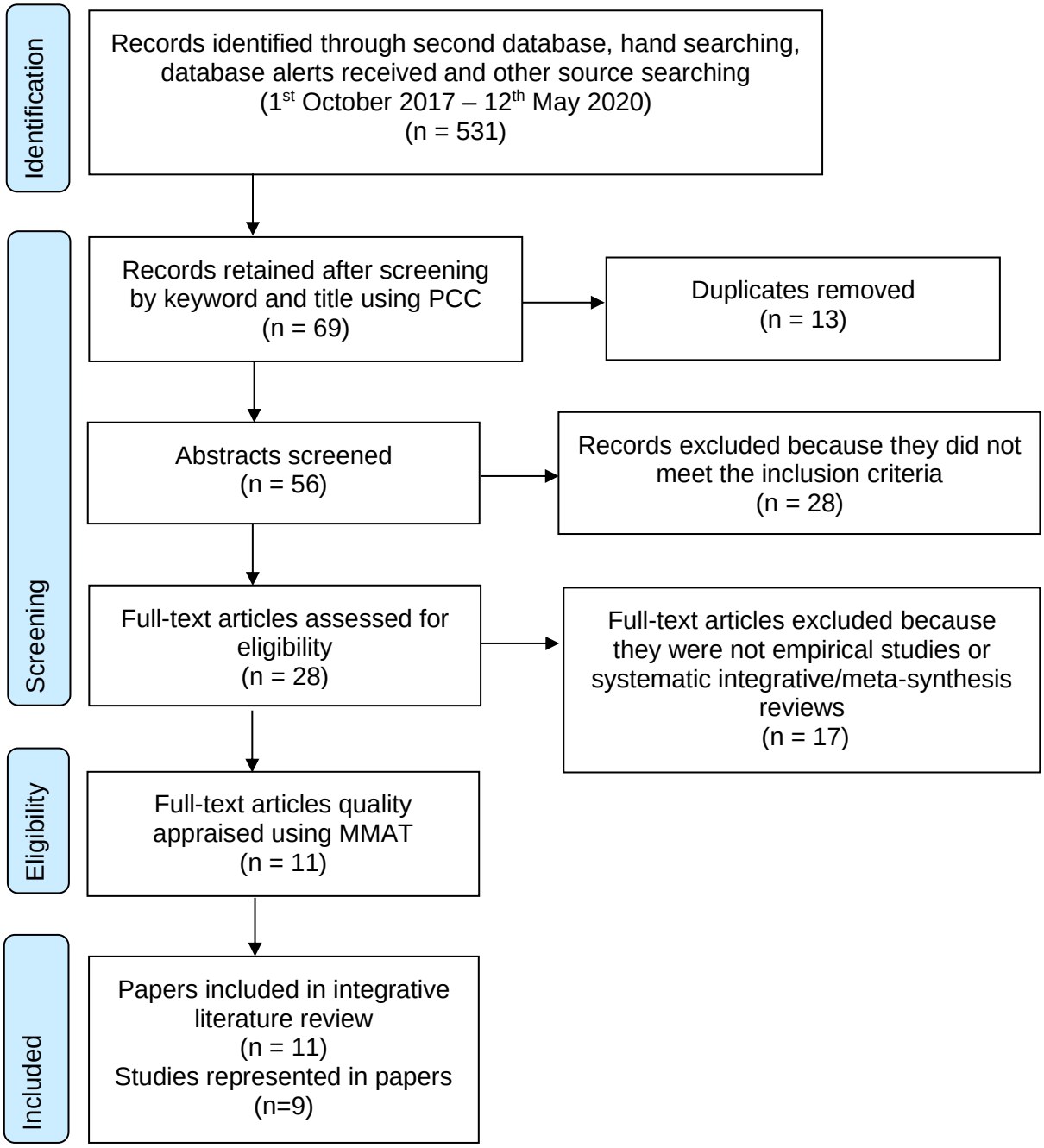
Appendix 1: Databases Searched and Records Identified (1st January 1988 to 12th May 2020)

Search Term	CINAHL	PsycINFO	PubMed Central (PMC) (PubMed Health) includes Ovid MEDLINE	Web of Science (now Scopus)	Discover More
1. Technology	6,082	47 (none – IT, ageing)	8,584	1,346,225	18,575, 922
2. medical technolog* OR "medical technology" OR "medical technologies" OR "medical equipment" OR "health technology" OR "healthcare technology"	40,926	No records in set	6,189	59,958	4,967,946
3. Child, medically fragile	715	142	24	113	11,630
4. "complex healthcare needs" OR "complex health care needs"	146	87	18	151	2,001
5. "Complex care" needs	164	No records in set	862	45,314	9,342
6. Home	148,449	207	2,332	327,694	4,979,049
7. Community					
1&3	4	172	26	29	
2&3	66	No records in set	29	59,771	
4&6	7	102	14	80	1,410
1&5		26	9	60	
6&2	1599	38	1649	19,626	905,691 469,965 with filters: Medicine, Public health
6&2 Filtered with age: Infant 1-23 months Child 2-5 years Child 6-12 years Adolescent 13-18 years Young Adult 19-24 years (where available, and where not available, Adults 19-44)	399	Not run – only 1 appropriate article in above	8,162 (even when excluded adults 19-44) As above to include 6&4OR5: 2,491 To include 6&4 with the word 'complex' removed to account for Special Health Care Needs: 2,567	As above to include 6&4OR5: 64,097	407,426 Filtered with age and includes 6&4OR5: 2,105 By journal article only: 1,295
1 OR 2 AND 3 AND 4 OR 5 AND 6 OR 7 (1988 onwards) (with filters all child, all infant, adult 19-44, in English) Major Heading – Community Health Service Removed adult 19-44 filter and Major Heading filter to obtain more relevant results – found that 'medical homes' is a key term	324,782 18,443 636 44,787				

Appendix 2: PRISMA Flow Diagram for the First Literature Search (9th June – 16th October 2017) (Adapted from Moher et al., 2009)



Appendix 3: PRISMA Flow Diagram for the Second Literature Search (1st – 12th May 2020)



Appendix 4: Mixed Methods Appraisal Tool (MMAT) (Pluye, 2011) Quality Appraisal Synopsis Table (2017 Literature Search) Including Quality Scoring (1-star to 4-star)

Type of study	Methodological quality criteria	Qualitative 2017 Literature Search # used data from the same study											
		Black et al. 2009 **3-star**	**Carnevale 2006** **4-star**	**De Lima 2015** **3-star**	**Diehl et al. 1991** **3-star**	**Dybwik et al. 2011** **4-star**	**Earle et al. 2006** **4-star**	**Gardner 2014** **3-star**	**Hobson & Noyes 2011** **4-star**	**Kirk 1999a#** **3-star**	**Kirk 2001#** **4-star**	**Kirk et al. 2005#** **4-star**	**Kirk & Glendinning 2004#** **4-star**
Screening questions	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Do the collected data address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?	N	Y	N	Y	Y	Y	Y	Y	N	Y	Y	Y
Key: Y = Yes; N = No; CT = Can't Tell													

MMAT 2017 Literature Search Continued/

Type of study	Methodological quality criteria	Qualitative 2017 Literature Search # used data from the same study									
		Kirk & Glendinning 2002# 2-star	**Lehoux et al. 2004 4-star**	**Levine 2005 1-star**	**Nageswaran 2017 3-star**	**Nishigaki 2016 3-star**	**O'Brien 2001 3-star**	**Rehm & Bradley 2005 3-star**	**Samwell 2012 1-star**	**Wilson et al. 1998 3-star**	**Woodgate et al. 2015 4-star**
Screening questions	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Do the collected data address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?	Y	Y	CT	Y	Y	Y	Y	CT	Y	Y
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	N	Y	N	Y	Y	Y	Y	CT	Y	Y
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?	N	Y	N	N	CT	CT	CT	CT	N	Y
Key: Y = Yes; N = No; CT = Can't Tell											

MMAT 2017 Literature Search Continued/

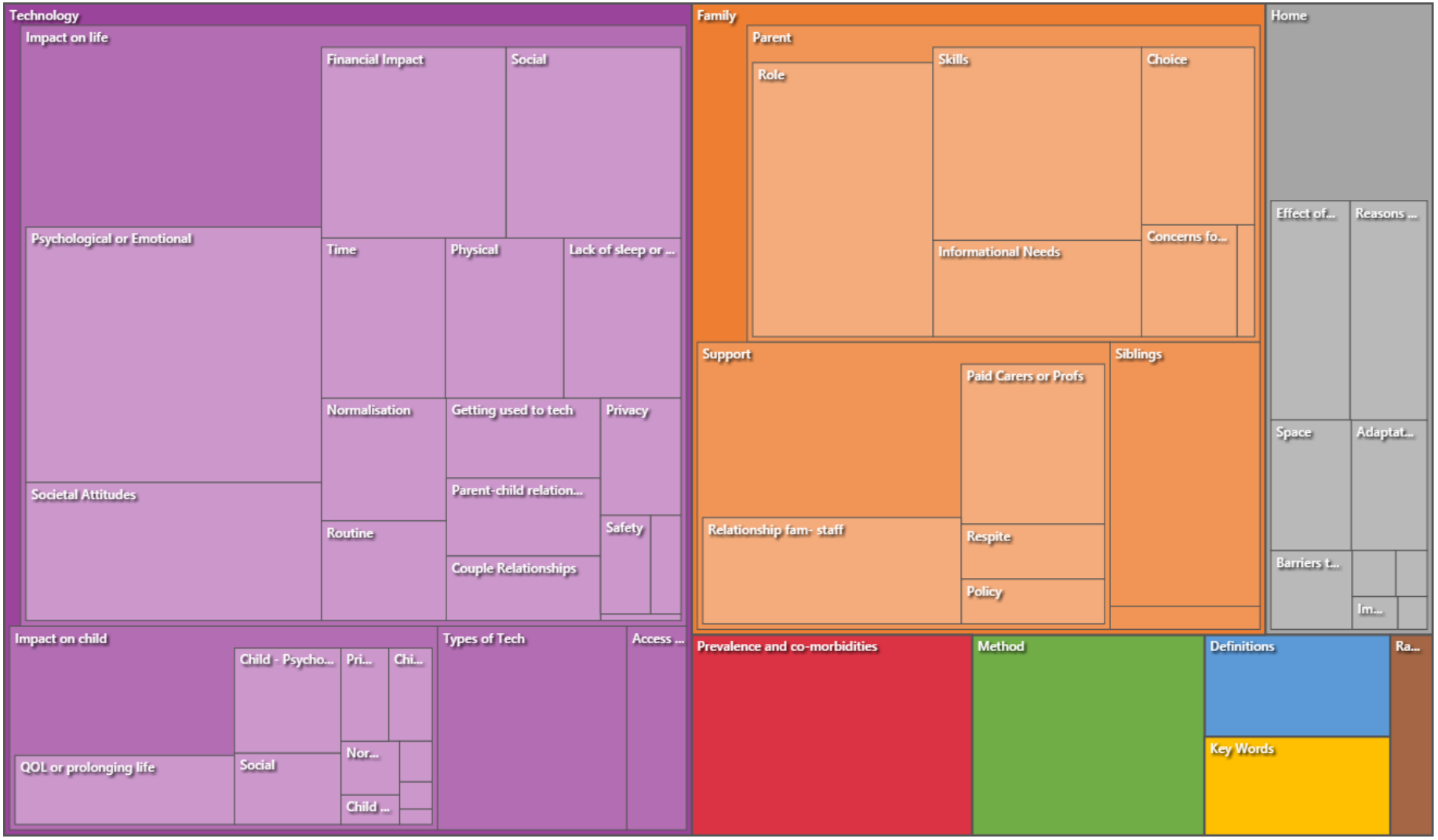
Type of study	Methodological quality criteria	Quantitative Descriptive 2017 Literature Search				Mixed Methods + used data from the same study				
		Paddeu et al. 2015 2-star	Bourke-Taylor et al. 2014 4-star	Nicholl et al. 2013 4-star	Sakashita et al. 2013 0-star	Toly et al. 2012+ 4-star	Toly, Musil & Carl 2012+ 4-star	Toly et al. 2017+ 1-star	González et al. 2017 1-star	Heaton et al. 2005 3-star
Screening questions	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Do the collected data address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?							N	Y	Y
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?							Y	CT	Y
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?							N	CT	Y
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?							N	N	N
2. Quantitative randomised controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?									
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?									
	2.3. Are there complete outcome data (80% or above)?									
	2.4. Is there low withdrawal/drop-out (below 20%)?									
3. Quantitative non-randomised	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?									
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?									
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?									
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable									

	follow-up rate for cohort studies (depending on the duration of follow-up)?									
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	N	Y	Y	N	Y	Y		N	
	4.2. Is the sample representative of the population understudy?	CT	Y	Y	N	Y	Y		CT	
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Y	Y	Y	N	Y	Y		Y	
	4.4. Is there an acceptable response rate (60% or above)?	Y	Y	Y	N	Y	Y		Y	
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?									Y
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?									Y
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?									N
Key: Y = Yes; N = No; CT = Can't Tell										

Appendix 5: Mixed Methods Appraisal Tool (MMAT) (Pluye, 2011) Quality Appraisal Synopsis Table (2020 Literature Search) Including Quality Scoring (1-star to 4-star)

Type of study	Methodological quality criteria	Qualitative 2020 Literature Search								Mixed Methods (reporting on qualitative findings) + used data from the same study	
		Boss et al. 2020 3-star	Carter et al. 2018 4-star	Castor et al. 2018 4-star	Currie & Szabo 2019 3-star	Imperial-Perez & Heilemann 2019 4-star	Israelsson-Skogsberg et al. 2018 4-star	Spratling & Lee 2020 3-star	Wilkinson et al. 2020 3-star	Toly, Blanchette, Al-Shammari, et al. 2019+ 2-star	Toly, Blanchette & Musil 2019+ 2-star
Screening questions	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Do the collected data address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	Y	Y	Y	Y	Y	Y	Y	Y	CT	CT
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?	N	Y	Y	N	Y	Y	N	N/A	N	N
Key: Y = Yes; N = No; CT = Can't Tell; N/A = Not applicable											

Appendix 6: Node Hierarchy Chart (generated November 2017)



Appendix 7: Data Extraction Summary of Reviewed Literature (ordered alphabetically)

Author(s), Year, Country	Aim of Study	Age of Children	Conditions or Diagnosis	Sample	Data Collection Methods	Analysis Methods	Key Findings	Limitations
Black et al. (2009), USA	To analyse the phenomenon of becoming a mother to a technology-dependent infant.	Up to 16 months old, corrected for prematurity	Medically fragile infants, or infants born to high-risk mothers	34 mothers	Longitudinal qualitative study using interviews	Content analysis and life course theory analysis	Maternal role and identity were key issues in navigating the difficulties of mothering a technology-dependent child.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Boss et al. (2020), USA	To explore the lived experiences of a nation-wide sample of families of children who have received paediatric home health care (PHHC).	Up to 18 years old	Medical complexity	48 parents	Qualitative study using semi-structured telephone interviews	Content analysis	High quality home care keeps children out of the hospital, permits them longer and fuller lives, and stabilizes the family infrastructure to permit physical, mental, and financial well-being.	Author reported: Not possible to know if parent report accurately reflects prescribing or provision of PHHC. Local variations in PHHC services could alter family experiences. Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Bourke-Taylor et al. (2014), Australia	To investigate the self-reported real-life costs, equipment needs, and associated characteristics of children who had the highest equipment and care needs.	2 to 12 years old	Cerebral palsy, complex needs, physical disabilities	29 families (hard to ascertain whether 29 parents or whether some participants were parent couples)	Quantitative descriptive study using surveys	Descriptive statistics and Spearman rho correlation	The equipment needs of young children with complex disability are extensive and out-of-pocket expenses and parental time to support participation in play/recreation excessive. Substantial financial support to offset costs are crucial to better support families in this life situation.	Author reported: Small sample size and challenges of verification for financial report. Reviewer identified: Parents/carers all recruited from the same early intervention centre.
Carnevale et al. (2006), Canada	To explore the moral dimension of family experience through detailed accounts of life with a child who requires assisted ventilation at home.	1 to 19 years old	Children who require assisted ventilation	11 families (38 family members: 11 children, 9 siblings, 11 mothers, 7 fathers and family as a whole)	Qualitative study using semi structured interviews and fieldwork observations	Thematic and Interpretive Analysis and Constant Comparison	The overarching phenomenon that best characterizes these families' overall experiences was 'daily living with distress and enrichment'.	Author reported: No perspectives gained from of parents who decided to limit mechanical ventilation and consequently allowed their children to die. Reviewer identified: Participants' all recruited from the same health institute, which is in a country where health services are state funded.

Carter et al. (2018), England	To consider the *#notanurse_but* videos in terms of the range, content, context, perspectivity (motivation), and affect (sense of being there) in order to inform the future direction of the campaign.	Age not reported	Children with complex healthcare needs	11 parents (10 mothers and 1 father)	Qualitative study analysing pre-existing *#notanurse_ but* video data	Narrative	Families have a sense of feeling different than "normal families".	Author reported: Research team rather than more diverse population acting as audience. Only materials created by parents available as data. Reviewer identified: Age of children not reported.
Castor et al. (2018), Sweden	To elucidate family members' lived experience when a sick child received home care from county- based primary healthcare services.	6 months to 14 years old	Sick children with cancer, chronic lung disease, congenital hiatal hernia, heart disease and Lyme disease	12 Families (4 children, 10 siblings, 23 parents)	Descriptive qualitative interviews, sometimes using photographs	Hermeneutic phenomenology	Care in the family's home is a useful complement to hospital care. Home care should be given with close attention to family members' needs and conditions, as positive effects of home care might be jeopardised when expectations and possibilities are not successfully shared.	Author reported: None Reviewer identified: No further limitations identified.
Currie and Szabo (2019), Canada	To co-construct new meanings and interpretations of parenting a child with complex disabilities by having an increased understanding of the struggles and barriers for parents.	Children 11 years of age and younger	Children with rare neurodevelopmental diseases	Fifteen parents (11 mothers and 4 fathers)	Qualitative study using face-to-face semi-structured interviews	Hermeneutic phenomenology Interpretive thematic analysis	Parents experienced silencing or being silenced within interactions with healthcare and social care systems and providers.	Author reported: Interview transcripts were not submitted to participants for member checking, as is congruent with hermeneutic phenomenology. Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Diehl et al. (1991), USA	To identify the needs of parents of children with medically complex needs from their own perception.	Birth to 21 years old	Children with medically complex needs	80 parents or carers	Qualitative study using focus groups	Ethnographic analysis and content analysis	Agencies and services were fragmented. Parents must be assertive to obtain the information and services that they require. Support groups are invaluable.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to context of data collection setting.
Dybwik et al. (2011), Norway	To explore the experiences of families giving advanced care to family members dependent on	8 to 78 years old	People who are ventilator-dependent	15 family members	Qualitative study using face-to-face, in-depth interviews	Constant Comparison	There is a large gap between family members' expectations and what the community health care services can provide, even	Author reported: Small sample. Transferability of findings to other countries may be limited due to differences in treatment, organisational

	home mechanical ventilation.						when almost unlimited resources are available.	issues and financing of HMV. Reviewer identified: No further limitations identified.
Earle et al. (2006), Canada	To explore the experience of home ventilation from the children's Perspective.	4.5 to 17 years old	Children and young people who have been home ventilated	5 children	Qualitative case studies using observations and semi-structured interviews	Constant Comparison	Children expressed their physical and emotional relationship with the ventilator. Other themes included the medicalization of childhood, being a child and hopes for the future. Unlike other study findings to date, the children in this study concluded that the technology was only one small part of their lives.	Author reported: Small sample. Longitudinal research is needed to examine the long-term effects of this technology on children throughout life, including the palliative care or end-of-life stage of home ventilation. Reviewer identified: Can't tell whether the collected data address the research question.
Gardner (2014), USA	To describe maternal caregiving and related strategies used by first-time mothers of young infants with complex health conditions (CHC) in the first 6 months after discharge.	Under 6 months old	Medically fragile infants with Complex Health Needs	8 mothers	Qualitative study using semi-structured interviews	Constant Comparison	The time-and-experience-mediated process of caregiving involved three phases of increasing confidence and expertise, developing in the context of decision- making responsibility. Mothering became predictable and integrated in everyday life by about 6 months after the infant's discharge home.	Author reported: Small sample size. Limited follow-up time (6 months). Reviewer identified: Insufficient consideration given to how the study findings related to the context of the data collection setting.
González et al. (2017), Spain	To assess perceived quality of life of home-ventilated children and their families as well as the problems they face in their daily life.	1 month to 18 years old	Children who use Home Mechanical Ventilation	41 Families (20 children)	Mixed methods study using questionnaires then a semi-structured open questionnaire	Descriptive statistics	Perceived QOL by children with HMV and their families is lower than that of healthy children. Parents are happy to care for their children at home, even though it negatively affects family life.	Author reported: Small sample size. Transferability of findings to other countries may be limited to due to different social and healthcare resources and infrastructure in other countries. Reviewer identified: Can't tell if analytical processes are relevant to address the research question. Can't tell if appropriate consideration given to how the study findings related to the context of the data collection

								setting or the researchers' influence.
Heaton et al. (2005), England	To examine families' experiences of caring for a technology-dependent child from a temporal perspective.	Up to 18 years old	Technology Dependent Children	36 Families (75 family members: 46 parents; 13 children; 15 siblings; 1 grandparent)	Mixed methods study using face-to-face semi-structured interviews, timeline drawings, diaries, questionnaires	Framework analysis and descriptive statistics	The care of technology-dependent children at home places considerable time demands on families. Families have little or no access to suitably trained carers who can provide technical care required in the home or away from the home to give parents and the whole family a break from caring where required.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Hobson and Noyes (2011), Wales	To describe experiences of fathering, parenting and caring for a child with complex healthcare needs.	16 months to 16 years old	Children with complex healthcare needs	8 Fathers	Qualitative study using face-to-face in-depth interviews	Burnard's Approach. Commonalities with phenomenology and content analysis.	Fathers enjoyed their caring role and found it rewarding and at times stressful. They instituted structured regimes. Performing intimate care posed specific challenges for which there is no guidance. Children's community nursing was highly valued. Fathers generally rejected the need for specific father-focussed services. Fathers reported positive relationships with their children and partners.	Author reported: Small sample size. Female researchers only which may have impacted upon fathers' responses. Reviewer identified: Fathers were all recruited from the same children's community nursing team.
Imperial-Perez and Heilemann (2019), USA	To describe the perceptions and lived experiences of mothers of infants who were discharged from the hospital after surgery for complex congenital heart disease but were then readmitted to the hospital.	Under 6 months old	Infants with complex congenital heart disease	10 mothers	Qualitative study using face-to-face in-depth interviews	Constant comparison	The category of "having to be the one" high- lighted mothers' experiences providing medicalized care at home to their infants after complex cardiac surgery while managing other responsibilities, such as employment, busy households, and parenting other school-age children. The role of the caregiver is vital but demanding.	Author reported: Small sample size. Reviewer identified: Mothers were all recruited from the same children's hospital. Although findings related to mothers' demographic characteristics of number of children at home, marital and employment status were explored, those of age, educational level and ethnicity were not explored.
Israelsson-Skogsberg et al. (2018), Sweden	To explore everyday life experiences of children and young people	4 years to 21 years old	Children and young people living with home mechanical ventilation (HMV), who have	9 children and young people	Qualitative study using photovoice face-to-face semi-	Content analysis	Everyday life on a ventilator can be described as including power but simultaneously as characterized by	Author reported: None Reviewer identified: No limitations identified.

	living with home mechanical ventilation (HMV).		neuromuscular diseases, lung diseases, congenital central hypoventilation syndrome, and other congenital disabilities		structured interviews		vulnerability to the outside world, comparable to balancing on a tightrope. Various types of technology, both information and communication technology (ICT) and vital medical technology, enabled the participants to engage with the world around them.	
Kirk, S. (1999a), England	To investigate how services can be developed to support families caring for children with complex health care needs, and to consider the challenges facing professionals working in the primary health care sector.	4 months to 17 years old	Children with specialised health care needs in the community	23 mothers, 10 fathers, and 44 professionals	Qualitative interviews	Constant Comparison	Considerable variation in the sources and levels of short-term care and home care services received by families, and in the division of responsibilities between health and social services for funding these services. Parents themselves adopted a major role in coordinating services and facilitating inter-professional communication.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Kirk, S. (2001), England	To assess how the transfer of responsibility from professionals to parents was negotiated, the tensions and contradictions that can ensue, and the implications for professional nursing roles and relationships with parents.	4 months to 17 years old	Children with complex health care needs who are technology-dependent	23 mothers, 10 fathers, and 44 professionals	Qualitative study using in-depth interviews	Constant Comparison	Professionals' expectations of parental involvement in the care of sick children role can act as a barrier to negotiation of roles. In this study, parental choice was also constrained initially by parents' feelings of obligation and by the lack of community services.	Author reported: Small study. Reviewer identified: No further limitations identified.
Kirk, S. et al. (2005), England	To explore parents' experiences of caring for a child who is dependent on medical technology, and in particular of performing clinical	4 months to 17 years old	Children with complex health care needs who are technology-dependent	23 mothers and 10 fathers	Qualitative study using in-depth interviews	Constant Comparison	Parenting a technology-dependent child alters the meaning of parenting. Professionals need to recognize that providing care has a substantial emotional dimension for parents.	Author reported: None Reviewer identified: No limitations identified.

	procedures on their own children.							
Kirk, S. and Glendinning, C. (2004), England	To explore the experiences of families caring at home for a technology-dependent child; to examine their needs for practical and other support; and to examine how far services are currently meeting these needs.	4 months to 17 years old	Children with complex health care needs who are technology-dependent	23 mothers, 10 fathers, and 44 professionals	Qualitative study using face-to-face, in-depth interviews	Constant Comparison	Services in the community were not sufficiently developed to support this group of families. Major problems were identified in the purchasing and provision of both short-term care/ home support services and specialist equipment or therapies in the community. Service provision could be poorly planned and co-ordinated at an operational level.	Author reported: None Reviewer identified: No further limitations identified.
Kirk, S. and Glendinning, C. (2002), England	To discover parents' and professionals' experiences of receiving and providing support in a context where parents rather than professionals are the expert caregivers.	4 months to 17 years old	Children with complex health care needs who are technology-dependent	23 mothers, 10 fathers, and 38 professionals	Qualitative study using face-to-face, in-depth interviews	Constant Comparison	Caring at home for a technology-dependent child involves parents carrying out complex clinical procedures which, in a hospital environment, would be undertaken by professionals. Nurses are likely to find themselves working with parents whose technical competence, at least in the areas of care required by their child, is as great as that of nurses.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to the context of the data collection setting or the researchers' influence.
Lehoux, P. et al. (2004), Canada	To determine how technology was supposed to be used versus how it was actually used.	25 to 82 years old	Adults who require antibiotic intravenous therapy, parenteral nutrition, peritoneal dialysis or oxygen therapy	16 Patients, 6 caregivers and 16 nurses	Qualitative study using interviews and observations	Constant Comparison	Patients are deeply ambivalent about the benefits and drawbacks of technology, and that these advantages and disadvantages are shaped by the various places in which the technology is used.	Author reported: Gender, inequality and the oppression of the interview process could have been explored and emphasised. Reviewer identified: No further limitations identified.
Levine, C. (2005), Canada	To explore the moral experience of ventilator-dependent life at home for children and their families.	Under 2 to 19 years old	Children who are technology dependent	38 parents; siblings and children	Qualitative study using semi-structured interviews and observations.	Although themes are mentioned, the data analysis method is not transparent.	Families live with uncertainty and attempt to create 'normal' home environments. They experience social isolation and their lives are constrained, raising the question of justice within society and within families.	Author reported: None Reviewer identified: Can't tell if the process for analysing the qualitative data was relevant to address the research question. Insufficient consideration given to how

								the study findings related to context of the data collection setting or the researchers' influence.
de Lima, M. F. et al. (2015), Southern Brazil	To highlight family strengths and weaknesses in terms of the care provided to children who are dependent on technology, and changes occurring following the return of these children to their homes.	5 months to 7 years old	Chronically ill TD children with more than 1 diagnosis	13 mothers; 1 maternal grandmother	Two-phase qualitative study using semi-structured interviews	Content analysis and thematic modality	Families experienced obstacles and conflict situations in their search for well-being and security. They experienced challenges in receiving integral and humanized care. There were gaps in the support provided by health services.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Lindahl and Kirk (2018), Sweden and UK	To analyse and synthesise the research that has investigated the experience of home in relation to home mechanical ventilation (HMV).	Adults and one child (age not reported)	Children and adults who depend upon home mechanical ventilation	1 child HMV user; adult HMV users; 79 parents; healthcare professionals and personal assistants (participants of most studies were not applicable to this study)	Systematic integrative review	Systematic integrative review	Technology alters the meaning of home through its structural and conceptual reconfiguration. The home space is experienced as both a home and a workplace which creates tensions and ambiguities for HMV users/families and care workers. HMV users and their families attempt to recreate a sense of home and identity while gaining control over space and decision- making. Nevertheless, the home is seen as the preferred place to live and close bonds can develop between the different actors.	Author reported: Papers published before 2010 excluded. Nordic countries are over-represented in the review which may influence the transferability of the findings. Children's perspectives are absent in the review. Reviewer identified: It is difficult to separate the perspectives of HMV users and their parents/carers from those of healthcare professionals and personal assistants as they are presented together.
Lindahl and Lindblad (2011), Sweden	To describe the existing qualitative research that examined family members' experiences when a child is dependent on ventilator at home.	Children (age not reported)	Medically Fragile Technology-Dependent Children	91 HMV dependent children, 24 siblings, 190 mothers and 2 grandparents	Qualitative meta-synthesis of mostly interview or observation studies.	Interpretive integration of qualitative research findings	Parents learned how to organize the daily life and how to incorporate the child's needs within the needs of the family; the siblings took an active role both in domestic chores and for the care of their sibling; both the parents and siblings gained appropriate	Author reported: None Reviewer identified: No further limitations identified.

							knowledge and skills for the child's care.	
Nageswaran and Golden (2017), USA	To describe the quality of home health care services for children with medical complexity, identify barriers to delivering optimal home health care, and discuss potential solutions to improve home health care delivery.	7 months to 16 years old	Children with medical complexity.	26 family caregivers; 18 home health nurses	Qualitative study using semi-structured interviews and focus group interviews	Thematic analysis	There are problems in the quality of home health care delivered to children with medical complexity (lack of skills in nurses and inadequate home health care) which contributes to caregiver burden.	Author reported: The measure used to define children with medical complexity has not been validated. Small sample size of nurses as recruitment was difficult. Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Nicholl et al. (2013), Ireland	To identify the types and range of technology children with complex needs use at home, and the challenges that parents faced in using this technology.	4 months to 10 years old	Children with intellectual disabilities and associated complex needs	177 parents	Quantitative study using questionnaires	Descriptive statistics	Families identified that 22 pieces of equipment were used by their child. Issues concerning the use and management of this technology were highlighted.	Author reported: The survey tool was newly developed. Study findings were dependent upon parents' recall at the time of data collection. Reviewer identified: No further limitations identified.
Nishigaki et al. (2016), Japan	To reveal Japanese mothers' changing perceptions towards their technology-dependent children in the home care setting.	Up to 19 years old	Children and young people who are technology-dependent	14 mothers	Qualitative study using semi-structured interviews	Constant Comparison	Mothers gradually accepted their child's disease and disability. The level of preoccupation with the child was affected by the mothers' management of care and their attitude towards the social participation of their child in home care. Mothers provided daily care almost without help from other family members. Professional support for mothers is necessary so that they can take breaks from care.	Author reported: Mothers who had unstable relationships with their children's primary doctors would not have been invited to take part in the study. Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
O'Brien (2001), USA	To explore families' experiences of providing long-term home care	3 to 12 years old	Children who have been technology-dependent and living at home for at least a year.	11 mothers and 4 parent couples	Qualitative study using unstructured interviews	Denzin interpretive ethnography and descriptive statistics	Families identified frequent change, uncertainty, and unpredictability in their lives. Attempts to increase stability involved the use of vigilance,	Author reported: None Reviewer identified: Insufficient consideration given to how the study

	for their child who is technology dependent.						advocacy, and reframing. Areas of challenge, change, and growth included making sense of life, managing daily life with technology, and maintaining a functioning family. Increased.	findings related to the researchers' influence.
Paddeu et al. (2015), Italy	To investigate how children suffering from congenital central hypoventilation syndrome affects mothers and fathers by producing poor sleep quality, high-level diurnal sleepiness, anxiety, and depression.	Up to 16 years old	Children with congenital central hypoventilation syndrome (CCHS) and healthy children.	Parents of 23 children with congenital central hypoventilation syndrome and parents of 23 healthy children	Quantitative study using Pittsburgh Sleep Quality Index (PSQI); Epworth Sleepiness Scale (ESS); Beck Depression Inventory II (BD-11); Beck Anxiety Inventory (BAI)	Comparison of the differences between the PSQI, ESS, BDII and BDI scores of the parents of healthy children and those with children who have CCHS were performed through Kruskal-Wallis statistical analysis.	Parents of children with CCHS had poorer sleep quality, greater sleepiness, and higher BDI-II scores compared to that of parents of healthy subjects.	Author reported: Small sample size. Subjective rather than objective data were measured. Reviewer identified: The sampling strategy is poor and is not appropriate for addressing the quantitative research question. The very small sample size has not been justified; The sample is not representative of the population under study. The rationale for why parents of ventilated children were recruited from an annual meeting in only one setting is not provided. There is inadequate reporting of sampling and recruitment of the control group. The number of outpatient centers where control subjects were recruited is not clear. There is no explanation as to why both mothers and fathers of typically developing children were available in outpatient centers at the same time. There is inconsistency in the reporting of the control group. Authors report both male and female for the control group in Table 1 yet state that parents 'completed the questionnaires while waiting for the sons' check-up in outpatient centers' (pg.

								1061). Inadequate reporting or consideration of whether mothers had depression before the birth of their child. Inadequate reporting or consideration of typical sleep disturbance caused by children in the 1-5-year-old age bracket; Although the measurements are appropriate, the very small sample size means that the findings about the small or medium differences of self-reported data between groups is unlikely to be representative.
Rehm and Bradley (2005a), USA	To compare families' experiences in raising children who were both medically fragile and developmentally delayed or disabled to published attributes of normalization.	Unknown ages but school aged	Children who are medically fragile or developmentally delayed.	26 families	Qualitative study using semi-structured interviews	Constant Comparison	Normalization might not be necessary or desirable for all. Families might or might not adhere to the same sociocultural values and expectations as professionals and providers, and therefore, goals of any particular person or family must be assessed individually and used to plan interventions and support.	Author reported: None Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Sakashita et al. (2013), Hawaii, USA	To survey children and youth with special health care needs (CYSHCN) preparedness for electricity failure.	9 months to 25 years old	Technology and electricity dependent children and youth with special health care needs.	50 parents and caregivers	Quantitative study using questionnaires	Analysis methods not made clear.	Technoelectric-dependent CYSHCN are poorly prepared for electrical power failure.	Author reported: None Reviewer identified: Sampling strategy not relevant to address the research question; sample not representative of the population under study; study measurements not appropriate; and study response rate not acceptable.
Samwell (2012), Scotland	To examine one mother's story of her son's journey from hospital to home.	18 months old	One child with complex care needs	Mother of 1 child	Qualitative single case narrative study	Analysis methods not made clear.	Each child with a continuing healthcare need poses a unique set of challenges for those who help plan the journey from hospital to home. The way in these	Author reported: Case study of only one child and mother. Reviewer identified: Can't tell whether the data collected, and the analysis

							services are planned and provided can be as important as the services themselves. Practitioners need to be sensitive to the family experience if they are to manage such complex and demanding situations effectively.	process were relevant to address the research question. Can't tell if appropriate consideration given to how the study findings related to the context of the data collection setting or the researchers' influence.
Spratling and Lee (2020), USA	To explore the daily care experiences of caregivers of children who require medical technology.	New-born up to age 21 years	Children who require medical technology who have chronic conditions.	9 primary family caregivers	Mixed methods study reporting on qualitative results from semi-structured interviews.	Interpretive phenomenology	Theme 1 was Knowing my child's normal and having confidence with daily caregiving. Theme 1 included a subtheme of Caregivers are proactive and advocates for their child. Theme 2 was This is much different from my child's normal…this is an emergency. Theme 3 was We cannot sleep, and we are exhausted.	Author reported: Sample size; Caregivers all recruited from the same hospital or clinic. Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Toly et al. (2012), USA	To examine family functioning and normalization in mothers of technology-dependent children following initiation of home care.	Up to 16 years old	Technology-dependent children	103 mothers (93.6%) at Time 1 / 82 mothers (89.1%) at Time 2; 12 months apart.	Two-phase mixed methods descriptive, correlational, longitudinal study using face-to-face interviews or questionnaires	Descriptive Statistics	Mothers of technology-dependent children are at high risk for clinical depression that may affect family functioning.	Author reported: Participants were solely mothers from one geographic region of the United States. Reviewer identified: No further limitations identified.
Toly, Musil and Carl (2012) USA	To examine the relationships of the technology-dependent child's severity of illness, mother's depressive symptoms, and normalization efforts with family functioning in families with a technology-dependent child twice over 12 months.	Up to 16 years old	Technology-dependent children	103 mothers (93.6%) at Time 1 / 82 mothers (89.1%) at Time 2; 12 months apart.	Two-phase mixed methods descriptive, correlational, longitudinal study using face-to-face interviews.	Descriptive Statistics	Family functioning remained stable over the 12-month period for families whose children remained technology-dependent. Mothers' depressive symptoms were the only predictor of family functioning at Time 1 and 2, but over 1 year, this was no longer the case.	Author reported: Generalizability limited because of convenience sample from one children's hospital. Reviewer identified: No further limitations identified.

Toly et al. (2017), USA	To describe the experiences of well siblings who are living in a family with a TD child.	21 months to 17.75 years old	Siblings of technology-dependent children	60 mothers	Mixed methods study but only reporting open-ended face-to-face interviews	Content analysis	Major themes of well sibling adjustment within the family unit were upside (altruistic, prosocial behaviours) and downside (negative internal and external processing behaviours).	Author reported: Proxy reporting by mothers of siblings' experiences. Reviewer identified: No further limitations identified.
Toly, Blanchette, Al-Shammari, et al. (2019), USA	To identify the day-to-day management problems and solutions employed by mothers of technology-dependent children.	Under 17 years old	Technology-dependent children	101 mothers	Mixed methods study but only reporting qualitative component.	Content analysis	Mothers of technology-dependent children and their children are highly resilient at dealing with life events in complex situations. These parent caregivers are experts at problem solving and adapting in challenging situations and need to be respected for these sophisticated capabilities.	Author reported: Participants were solely mothers from one geographic region of the United States. Reviewer identified: Insufficient consideration given to how the study findings related to context of the data collection setting or the researchers' influence.
Toly, Blanchette and Musil (2019), USA	To explore what is most helpful and least helpful for mothers who care for their technology-dependent children at home.	Under 17 years old	Technology-dependent children	93 mothers	Mixed methods study but only reporting qualitative, descriptive component.	Content analysis	The presence of support as most helpful. In particular, emotional support from family such as parents, in-laws, siblings, cousins or well-siblings of the TD child, support from nurses and emotional support from their partner were subthemes most often reported.	Author reported: Participants were solely mothers from one geographic region of the United States. Reviewer identified: Insufficient consideration given to how the study findings related to context of the data collection setting or the researchers' influence.
Wilkinson et al. (2020), England	To portray mothering of a child with complex health care needs.	Children (age not clear)	Child with complex health care needs	Mothers and a father (no. not clear)	Analysis of a purposive selection of parent-recorded video diaries	Interpretative, inductive qualitative analytical approach using a data extraction sheet	Mothering a child who has complex health care needs extends normative ideas of mothering and motherhood. The therapeutic landscape of home can be a site of struggle relating to physical and emotional labour.	Author reported: The videos were created for a specific audience and are therefore not completely naturalistic. Video data does not provide a complete picture of 'real life'. Reviewer identified: This paper was to address methodological considerations, so did not describe the content of the videos, nor make explicit the age of the children represented by their parents.
Wilson et al. (1998),	To identify the core variable of	5 to 13 years old	Children who are medically fragile	16 mothers	Two-phase qualitative	Constant Comparison	Mothers in this study were knowledgeable and	Author reported: None.

Canada	absolute involvement, describing the provision of mothers' self-determined standard of care for her child.				study using telephone interviews		committed to caring for their children and did not wish to re-hospitalize their children. Mothers in this study did not perceive sole responsibility for their child's care, but believed they shared responsibility with caregivers.	Reviewer identified: Insufficient consideration given to how the study findings related to the researchers' influence.
Woodgate et al. (2015), Canada	To understand the roles that parents assume in parenting their children with complex care needs.	6 months to 26 years old	Children with complex care needs	39 mothers and 29 fathers	Qualitative study using interviews, photovoice and ecomap	Thematic analysis	Parents of children with complex care needs take on more roles as well as work more intensely at these roles than parents of healthy children. They lack adequate services and supports necessary to help them in their role of intense parenting.	Author reported: Differences in how parental roles vary based on the type of their children's complex care needs were not explored. Reviewer identified: Participants were parents recruited via a primary integrated health and social services community agency in one major city in Canada only.

Appendix 8: Overview of Recruitment Process

Preparation of materials including project flyer, invitation letter, participant information sheet & consent/assent forms (for all categories of participant), and draft interview schedules.

Contact the **Management/Board of Trustees of third sector charity organisations** to explain the purpose of the study and ascertain whether they are willing to advertise the study.

Submit above documents along with the **Research Proposal** and an **Application for Ethical Approval Form (RO-GOV-05F)** and **charity approvals** to **Edge Hill University, Faculty of Health and Social Care Research Ethics Committee (FREC).**

Once necessary **ethics approval has been granted**, recruit participants via the following charities and children's hospices in the North West of England:

- **Together for Short Lives**
- **WellChild**
- **Claire House Children's Hospice**
- **Derian House** (birth-<16 years); **The Lodge** 16-25 years)

If recruitment slow or unsuccessful from the above, then contact:

- **Rainbow Trust Children's Charity**
- **BreatheOn UK**
- **Hospice UK**
- And other third sector charity organisations and hospices

After reading the **information flyer**, acquired through above organisations, potential participants, who are initially likely to be parents will use their preferred method to contact me via the telephone/email/postal address provided in the flyer to ask any questions and confirm their own/their child's interest in taking part in the study. **Snowball sampling** will be employed, so other relevant potential participants may contact me via the same route and experience the same processes that follow.

I will then send participant information sheet and consent/assent form(s) via the participants' preferred contact method to further inform their decision and will make contact again one week later to ascertain whether or not they still wish to participate. I will indicate that they have the choice of using their own device to take the photographs.

If the participant **IS using their own device/s** to take the photographs, I will give instructions again (in addition to instructions in the participant information sheet) about how the participant should take the photographs. I will establish which method (electronically or via personal contact) the participant would prefer for transferring the photographs to me so that I can arrange for them to be printed before the interview. I will arrange a convenient date to conduct the auto-driven PE interview 1-2 weeks later.

If the participant **IS NOT using their own device/s,** I will arrange a date to deliver a camera/s for each person in the family who wishes to participate. I will give instructions again (in addition to instructions in the participant information sheet) about how the participant should take the photographs. I will arrange a convenient date to return 1-2 weeks later to transfer the photographs to my password protected laptop and then another date to return 1-2 weeks later to conduct the auto-driven PE interview.

Appendix 9: Data Management Plan (December 2016)

How does medical technology effect life at home for children and young people with complex healthcare needs and their family?

Project Name How does medical technology effect life at home for children and young people with complex healthcare needs and their family?
Principal Investigator / Researcher Tracy Mitchell
Description Aim: To determine how medical technology effects life at home for children and young people with complex healthcare needs and their families. Research Question: How does medical technology effect life at home for children with complex healthcare needs and their family? A proposed qualitative study for an Application to Register for a Research Programme Leading to The Award of Doctor of Philosophy at Edge Hill University
Institution Edge Hill University

Data Collection

What data will you collect or create?
The type, format and volume of data that I will collect or create is as follows:
Raw data will be qualitative in the form of:

- Auto-driven photographs (photographs taken by participants prior to interview) of medical technology in the home
- Field Notes
- Digital audio-recorded auto-driven photo-elicitation family-based interview and transcript data (Approx. 20 participants)
- Participant contact details
- Consent forms

Reduced data

- anonymised and coded transcripts - backed up in NVivo

Published data

- Anonymised photographs and participant quotes will be included in the Final Thesis and
- Journal articles and conference presentations

Other

- Project flyer
- Invitation letter (differentiated to a language style that is accessible to the specific age group/cognitive
- ability of the technology-dependent child, other child participants, family who live with the technology-dependent child and family who do not live with the technology-dependent child)
- Participant Information Sheet (which will include information about my role, and the purpose, aims and objectives of the research and how it will be undertaken, the inclusion criteria, issues of anonymity and confidentiality and the expected benefits and risks)
- a Consent/Assent Form (for all categories of participant)
- Draft Interview Schedule (which will be a short list of the topics or issues that I wish to cover during the interview)

Documents will be in the format of Microsoft Word or Excel, PDF or JPG or PNG. Word and Excel can open previous versions of documents, which will enable long term access.
Identifying data will be stored separately to raw, reduced and published data. All data will be stored securely on the Edge Hill University network, which is encrypted, and password protected, or my own password protected computer. Anonymised transcripts will also be stored within my password protected NVivo account. QSR does not collect any details of the data that I am working with when I use their software products. QSR only collect personal information about me, which is subject to the Data Protection Act 1998, and from 25 May 2018, the EU Directive 2016/679 for the General Data Protection Regulation ("GDPR"). The actual project data is stored only in the projects or files that I direct the software to save the data.

The volume of data in terms of storage, back up and access will be quite small, so there will be sufficient storage on the Edge Hill network, even if participant photographs are large files.
I estimate that the maximum storage needed for this project will be 2.5 GB. This includes the maximum estimation of 200 photographs (taken by the participants to inform the interview), 20 interview transcripts and audio recordings.
There is no existing data that can be reused, as previous studies have only been conducted in the main with parents, to explore the impact of caring at home for a technology-dependent child with LLC or CHCN. Very few studies have involved technology-dependent children and young people or siblings, and no studies were identified that have included the wider family, such as grandparents, aunts, uncles etc. No study has been identified that has explored specifically how children and young people with complex healthcare needs and their immediate and wider family experience medical technology in the home.
It is doubtful that the raw data can be shared as it would be too identifiable, given that the population of children and young people who are technology-dependent and who have a life-limiting condition or complex healthcare need is very small.

How will the data be collected or created?
The data will be created via a method of qualitative auto-driven family-based photo-elicitation interviews.
Photographs of medical technology in the home will be taken by the research participants via a camera which will be provided, or their own camera, phone, iPad etc. Photographs will be uploaded to my drive on the university server from the SD card/email etc. For those parents wishing to use their own device, we are currently identifying a method of secure transfer.
I will transcribe the digitally recorded interviews with children/young people and their family members myself and save them onto my drive on the university server.
I will develop risk management protocols for data management and storage with the support of my supervisory team.
The main folder for the project 'How does medical technology effect life at home for children and young people with complex healthcare needs and their immediate and wider family?', kept on the university drive, will be named GTA (abbreviation of Graduate Teaching Assistant), and there will be sub folders named Audio, Analysis, Contracts, Correspondence, Data Collection (will include expression of interest spreadsheet and a participant spreadsheet), Dissemination, Ethics, Literature, Approved Docs for Use (Participant Information Sheet, consent forms etc.), Proposal, Supervision, Transcripts, Viva. Some folders will contain a Previous Versions folder (named with earlier dates) - only the correct and most current version will be available in the top folder.
Coding will be carried out using NVivo. Coding descriptors will be assigned to each node to explain the inclusion criteria for each code.
The time references, geographic location, inclusion/exclusion criteria's etc. will all be included within research proposal document, and subsequent dissemination documents.
I will be responsible for the consistency and quality of the data, and upon completion of my GTA position, will pass the responsibility for future proofing the data to my supervisory team/Director of Studies, if I do not remain in employment with Edge Hill University.
All data will be managed in accordance to Edge Hill University Guidelines (e.g. EHU Framework for Research Ethics), legislation such Data Protection Act 1998, HM Government (2015) information sharing guidance, Health Research Authority Standard Operating Procedures (http://www.hra.nhs.uk/documents/2016/10/res-standardoperating-procedures-version-7-1.pdf), as well as my professional registration procedures under the Health and Care Professions Council.

Documentation and Metadata

What documentation and metadata will accompany the data?
As the Principle Investigator of the project, I will create all documentation and metadata to ensure that it can be read and interpreted in the future, to include:

- study description - information about the context of the data collection such as bibliographic citation of

- the study and data, scope of the study (topics, geography, time), methodology of data collection,
- sampling and processing, data access information, and information on accompanying materials
- data file description - information on data format, file type, file structure, missing data, weighting
- variables and software
- variable descriptions (http://www.data-archive.ac.uk/create-manage/document/metadata)

in accordance with Edge Hill University's research data management guidelines, the Data Protection Act, Research Governance Frameworks etc.
Data Preservation - http://www.data-archive.ac.uk/media/2894/managingsharing.pd

Ethics and Legal Compliance

How will you manage any ethical issues?

Consent to share the data generated (anonymised) will be obtained before data collection commences. Participant identifier numbers will be ascribed to interview transcripts and audio files. It is possible that the participants or the home of the participants may be identified from the photographs of medical technology in the home. Participants will be informed of this and consent will be obtained prior to the interview and during the interview, in case there are any photographs that the participants do not wish to use. Participants will be able to withdraw their consent for each photo to be used for 1 week following the interview, as analysis may have then begun.
Participants will be informed, and consent obtained to disseminate the anonymised findings of the study via publications, conferences etc.
The only people who will have access to identifiable data will be myself and my Director of Studies/Supervisory Team.
All data will be stored securely in a password protected computer or a locked drawer (although I plan to scan consent forms into the computer and destroy paper versions via confetti shredder).
Data will be kept for 10 years.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

As the Principle Investigator, I will own the data. The data will be too identifiable to be reused by third parties. Data will be shared via the progression and final Viva's and publications will be made throughout the project -co-authored by my Director of Studies and Supervisors/Advisor.

Storage and Backup

How will the data be stored and backed up during the research?

Data collected in anticipation of the interview (participant details and photographs of medical technology in the home) and during the interview (audio files and eventual transcripts) will be stored on the University encrypted network and my password protected computer. Participant contact details, consent and assent forms (that will be scanned and then the paper versions destroyed via confidential waste) will be stored separately from other research data. Ongoing versions of registration documents have been/will be emailed to my supervisory team/or to myself. Literature to inform the registration document/future registration documents and thesis is stored on my University account, home computer and in Mendeley (all password protected). Interview data (photographs, audio recordings and transcripts) will be stored on the University network, which is encrypted, and password protected and which I can access from home. Audio recordings will be destroyed once transcribed and checked for accuracy. Photographs and transcripts will be backed up in NVivo, which will be used for data management.
Each section of my proposal, thesis etc. will be emailed to myself regularly (all will be anonymised).
Organisational (EHU Data Management Guidelines, professional (HCPC Standards of Conduct, Performance and Ethics), national and international legislation and guidance (HM Government (2015) information sharing guidance, Data Protection Act 1998, HRA Confidentiality, Privacy and Data Protection etc.) will be adhered to at all times.

How will you manage access and security?
The data stored on the University network is encrypted and password protected, and my home computer is password protected (a strong password) and only used by me. Only I will have access to the physical data. To manage the risks associated with physical data, all electronic devices are password/code protected and drawers locked. Any paper versions of documents will be destroyed via confetti shredder or university confidential waste.
Participant identifiers will be ascribed to consent forms, audio recordings and transcripts.
I will adhere to lone working policies when out in the field. we are currently identifying a method of secure transfer for any photographs, although currently expect to use a card reader and password protected laptop. The password protected laptop will not be left unattended at any time.

Selection and Preservation

Which data are of long-term value and should be retained, shared, and/or preserved?
This document was generated by DMPonline (http://dmponline.dcc.ac.uk) 3 of 4
Data will be kept on the Edge Hill University encrypted network for 10 years.

What is the long-term preservation plan for the dataset?
Any dissemination publications will be kept on the University research repository. Anonymised data and documents created in Microsoft are future proofed in the sense that future Microsoft versions are backward compatible. In accordance with Data Protection legislation, the data that will be collected and processed should only be used for the purpose for which it was created -i.e. the data collected for this project can only be used for this project.

Data Sharing

How will you share the data?
Although RCUK Common Principles on Data Policy states that data should be made openly available, as the research will be using a qualitative method with a small number of participants, from a very specialised (and small) population, the raw data will not be made publicly available as it will be too identifiable. Anonymised and coded data will also possibly not be made available, as the ethical principle 'do no harm' cannot be guaranteed if participants can be identified. The balance of traditional confidentiality with contemporary openness will be constantly assessed throughout the project. The research findings will be published in research journals, and a brief abstract possibly uploaded to the university repository.

Are any restrictions on data sharing required?
Yes, the raw data will never be able to be shared as it will be too identifiable. The coded data is also unlikely to be able to be shared with the population of technology-dependent children being so small.

Responsibilities and Resources

Who will be responsible for data management?
As the Principle Investigator, I (Tracy Mitchell) will have responsibility for the management of data.

What resources will you require to deliver your plan?
Lockable drawers; Access to the University Network, with enough personal storage space; Ongoing access to NVivo and Mendeley.

Appendix 10: List of Documents Sent to the Faculty Research Ethics Committee for Ethics Approval

ETHICS APPROVAL APPLICATION FORMS

- Academic Supervisor Checklist
- Research Ethics Committee (REC) Application for ethical approval (RO-GOV-05F) which set out the governance and ethical regulations applicable to the study.
- Research Proposal for FoHSC FREC Review

PARTICIPANT FORMS

- Flyer
- Invitation Letter

Information Sheets (x8 including TfSL)

- Information for Adults
- Information for Parents and Carers Consenting for Children or Young People aged 5 – 15 years
- Information for Children aged 5-10
- Information for Young People aged 11-15
- List of Support Organisations
- Together for Short Lives Advocacy Service Leaflet (upon request).
- Information for Adults with a Personal Consultee
- Information for Personal Consultees

Consent/Assent/Declaration Forms (x6)

- Adult Consent Form
- Adult Consenting for a Child or Young Person aged 5 – 15 years Form
- Child 5-10 Assent Form Consent Form
- Young Person 11-15 Assent Form
- Adults with a Personal Consultee Consent Form
- Personal Consultee Declaration Form

Interview Structures (x5)

- Interview Structure for Adults who rely upon Technology
- Interview Structure for Adults (Parents/Relatives/Carers)
- Interview Structure for Children aged 5-10
- Interview Structure for Young People aged 11-15
- Interview Structure for Adults who have a Consultee

Appendix 11: Study Flyer

Does medical equipment affect your life at home?

Would you be interested in taking part in a study?

What is the study about?

The study is about how medical equipment affects life at home for children, young people and young adults with complex healthcare needs and their family.

What sort of medical equipment?

The study focuses on medical equipment needed by children with complex health care needs (for example: tracheostomy/gastrostomy/jejunostomy, suctioning, IV medication, enteral feeding, mobility aids, oxygen, colostomy, catheterisation, peritoneal dialysis, monitors etc.)

Who can take part in this study?

You can take part and share your views and experiences of living with medical equipment at home with me if you can speak and understand English sufficiently fluently (using communication aids if you need them) to be able to tell me what life with medical equipment at home is like AND you are:

- **Aged 5-25 years** and have used at least **two pieces of medical equipment** to keep you healthy, for at least **three months,** at **home** in the **United Kingdom.**
- **A parent, relative or carer** of a child, young person or young adult who meets the above criteria. If you do not live with or care for the child, young person or young adult in their own home, you must have provided some care for them in your home for at least three months.

What will I be asked to do if I take part in this study?

If you decide to take part in the study I will ask you either to:

1. **Take some photographs about your life at home with medical equipment AND take part in an interview about your views and experiences of life at home with medical equipment.**

OR

2. **Just take part in an interview about your views and experiences of life at home with medical equipment**.

What should I do if I am interested?

If you want to find out more about the study, you can contact me on the details given below and I will explain about the study in more detail:

Tracy Mitchell

Graduate Teaching Assistant/PhD Studentship
Faculty of Health & Social Care, **Edge Hill University,** St. Helens Road, Ormskirk. L39 4QP

01695 650960
Tracy.Mitchell@edgehill.ac.uk

Appendix 12: Invitation Letter to Parents

Tracy Mitchell
Graduate Teaching Assistant/PhD Studentship
Faculty of Health & Social Care
Edge Hill University
St Helens Road, Ormskirk
L39 4QP

01695 650960/654353
tracy.mitchell@edgehill.ac.uk

Invitation Letter Date……

Dear ……

Thank you for your interest in taking part in **The Life at Home with Medical Equipment Study.**

This information pack contains information that tells you about the study.

In the information pack I am sending you the following sheets: (Note: Only the relevant ones will be sent to the family and listed below)

- *Information for Adults*
- *Information for Children aged 5-10*
- *Information for Young People aged 11-15*
- *Information for Adults Consenting for Children or Young People aged 5 – 15 years*
- *Information for Adults with a Personal Consultee*
- *Information for Personal Consultees*

Please read the information sheet.

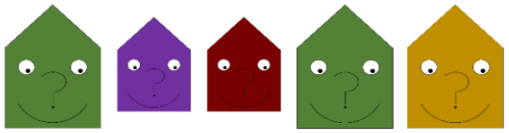
If you would like to take part in this study, would like any further information about the study or have any questions, please contact me via the details given above.

Kind Regards

Tracy Mitchell

Appendix 13: Information Sheet for Adults

Edge Hill University



The Life at Home with Medical Equipment Study

Information for Adults

An invitation to participate

My name is **Tracy** and I would like to invite you to take part in a study exploring how different family members experience medical equipment at home. Before you decide whether to take part or not, it is important for you to understand what the study is about, why it is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. If anything is not clear or you need more information, then please feel free to contact me. My contact details are at the bottom of this form.

Why have I been invited to take part?

I am asking you because I think you can tell me what life with medical equipment at home is like. This is either because:

- You are **aged 16 - 25 years** and have a medical condition that causes you to currently rely upon at least **two pieces of medical equipment** to keep you healthy. And you have used this equipment **at home**, in the United Kingdom, for at least **three months.**

Or

- You are a **parent, relative or carer for a child aged 5 - 25 years** with a medical condition that causes them to currently rely upon at least two pieces of medical **equipment** to keep them healthy. They will have relied upon this equipment **at home (or in your home, if you do not live with or care for the child in their own home)**, in the United Kingdom, for at least **three months.**

Do I have to take part?

No, your participation in this study is entirely voluntary.

What will happen to me if I agree to take part?

If you do decide to take part in this study, you can choose to either:

1. **Take (or direct the taking of) some photos about your life with medical equipment at home and then talk to me in an interview about them, OR**
2. **Just talk to me in an interview about your life with medical equipment at home.**

Taking the photos: Taking the photos will probably take around 30 minutes. If you live within the North West of England, a digital camera can be provided if you do not have or do not want to use your own phone/camera/tablet. Please do not take photos that include children or adults outside of the family without their permission. Once you have taken your photos you can decide which ones you would like to discuss with me during an interview, which will be done within two weeks of you taking the photos. I suggest you choose up to 15 photos. We will discuss when and how your chosen photos can be transferred securely to me (e.g. via email to my University email account or via card reader to my password protected laptop).

Before the interview, I will ask whether you give consent to the use of your photos within publications and presentations and for comparison in the future studies of my supervisory team and I. You will decide which (if any) photos I can use in this way and I will only take photos that you are happy about back to the University with me.

You can also share any older photos (or drawings) that, for example, show how the home or equipment has changed over time, if you wish. During the interview I will ask you to show me your photos and share your views and experiences of what life with medical equipment at home is like.

The interview: You do not have to take photos to take part in an interview, but you do need to be able to speak and understand English sufficiently fluently (using communication aids if you need them). The interview will be at home, at a convenient time for you, unless you would prefer for it to be somewhere else. If you live outside of the North West of England, the interview is likely to be either by Skype or telephone.

Before we start the interview, I will ask you to sign a consent form (or email your consent to me) to confirm that you have read and understand this information sheet and have had the opportunity to ask questions. I will ask whether you give permission for me to audio-record the interview so that I can remember the important things you tell me. I will also ask whether you give consent to the use of some of the (anonymised) things you say within publications and presentations and for comparison in the future studies of my supervisory team and I.

During the interview, I will ask you to share your views and experiences of living at home with medical equipment. The interview might take between 20-60 minutes depending on how much you have to tell me.

Although you will only need to take part in one interview, I might be interviewing other people in your family. For those living in the North West of England, this means I might visit your home a few times to talk to them.

I plan to have finished the study and have written the report by July 2019. Let me know if you would like me to send you a copy of the short report.

What are the possible benefits of taking part?

I hope that you will enjoy taking part in the study but it is unlikely that there will be any direct benefit for you or your family. By helping me to understand how medical equipment affects life at home I hope to influence how services and equipment are planned, developed and delivered to best support families like yours.

What are the possible disadvantages and risks of taking part?

There are three things that you need to consider:

1. Being part of the study will take up some of your time.
2. You might become upset when talking to me about your experiences of medical equipment in the home and thinking about your illness or your child's illness. I am an experienced researcher and will ensure that you are supported to talk about your experience. I can give you a list of who you can contact to ask for advice and support. If you do become upset, I will give you the option of deciding if you would like to pause the interview, move onto another question, end the interview or reschedule it for another day. I will respect your decision.
3. Although all personal (identifying) data will be removed when typing up your interview, if you or someone from your family have shared photos with me, they could lead to people who know you/your family, your home or the equipment identifying that you or someone from your family has taken part in the study. I will manage this risk very carefully. If there are photos that could identify you/your child or family, or other people who might not like to appear in presentations and publications, I can edit or crop these to take out identifying information if you wish.

What if I change my mind?

You can withdraw your information if you no longer wish for it to be included in study up to 7 days from the time of your interview, without having to give a reason. I cannot remove information from my study such as what you said or your photos after 7 days as I will already be using it in my analysis.

Will my taking part be kept confidential?

Yes. I will be the only person who will know what you said unless someone from your family is listening when you are talking to me. I will not tell your family members or anyone else what you have said during the interview. I will take great care of the information that you share with me and will not identify you in any publication even if I use some of the words you shared with me.

Your personal details, photographs or drawings, interview recordings and transcripts will be kept securely in a locked drawer or computer with a password that no one except me knows.

Usually everything you tell me is kept confidential but that I cannot keep things confidential if you disclose any information that suggests that you or others have been harmed or are at risk of harm.

Who is funding this study?

The research is sponsored and funded by Edge Hill University as part of my PhD programme of study.

Who has reviewed the study?

This study has been reviewed by the Faculty of Health and Social Care Research Ethics Committee (FREC) at Edge Hill University.

What if there is a problem or I want to make a complaint about the study?

If you are unhappy with the research in any way, please tell me. I will try to put things right. If you do not want to speak to me, you can contact Bernie Carter, who is Professor of Children's Nursing and my Director of Studies on 01695 657771 or email bernie.carter@edgehill.ac.uk.

If you would rather speak to someone outside of the research team, you can contact Professor Clare Austin, who is the Associate Dean, Research & Innovation on 01695 650772 or email austincl@edgehill.ac.uk

If you would like to take part in this study, would like any further information about the study or have any questions, please contact me:

Researcher: Tracy Mitchell

Graduate Teaching Assistant/PhD Studentship, Edge Hill University

01695 650960

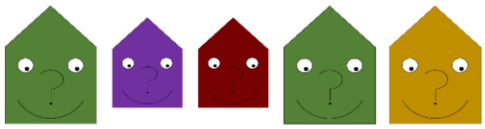
Tracy.Mitchell@edgehill.ac.uk

Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New Zealand).

Thank you for taking the time to read this information sheet and for considering taking part in this study!

Please keep this information sheet

Appendix 14: Information Sheet for Adults Consenting for Children



The Life at Home with Medical Equipment Study

Information for Adults (Parents and Carers) Consenting for Children or Young People aged 5-15 years

Please read with the information sheet most appropriate for your child:

- Information for Children aged 5-10
- Information for Young People aged 11-15

My name is **Tracy** and I am responsible for this research study. The study is exploring how different family members who have a child, young person or young adult aged 5-25 years with a medical condition that causes them to currently rely upon at least **two pieces of medical equipment** to keep them healthy experience medical equipment at home. The child, young person or young adult will have used this equipment **at home**, in the United Kingdom, for at least **three months.**

This information sheet is for adults who are consenting their child or children aged 5-15 years to take part in the study. If anything is not clear or you need more information, then please feel free to ask me.

Does my child have to take part?

No, it is entirely up to them to decide whether they want to take part or not. Your child aged 5 years or over can take part even if the child or young person who depends on medical equipment does not want to take part. Your child can be part of the study even if they cannot or do not want to take photos. They can take part in the interview and can use communication aids if this is how they communicate. It is fine if only one member of your family or all family members aged 5 years or over decide to take part. I will not ask your child or children to take part without talking to you first.

What will happen to my child if they take part in this study?

If your child wants to take part in this study, they can choose to either:

1. **Take some photos (or direct the taking of some photos) about their life at home with medical equipment and then talk to me in an interview, OR**
2. **Just talk to me about life at home with medical equipment in an interview.**

What do I need to do if my child wants to take photos?

If your child wants to take or direct the taking of photographs of life at home with medical equipment for the study, it will probably take them around 30 minutes to do this.

Please will you make sure that they do not take photographs of other children or adults without their permission.

Before I interview your child, they will need to decide which photos are the most important ones they would like to discuss with me. They might like your help in deciding up to 15 photos.

A digital camera can be provided if they live in the North West of England and do not have or do not want to use their own phone/camera/tablet.

What do I need to do if my child just wants to talk to you?

You will need to consent for your child or children to take part in the study if they are younger than 16 years old.

The interview with each child will take around 20 minutes, although the interview can be as short or as long as they need and we can stop at any time they wish.

If I am interviewing your child and other members of the family, I will work out how long I need to be in your home (or on Skype/the telephone) and we can arrange the time to suit you.

Your child can choose for you to be present during their interview but I would like your child to be able to tell their own story of their experiences.

Your child's assent (permission) to take part

Before the interview starts, I will spend time making sure that your child understands what the study is about and what it will involve for them. I will make it clear that they do not have to take part. I will explain why it is important for me to get their permission.

Once I am sure that your child understands what the study is about and says they would like to take part, I will carefully go through the assent (permission) form. Your child can give assent by saying yes or by ticking the boxes or writing their initials and name on their assent form.

What if there is a problem or I want to make a complaint about the study?

If you are unhappy with the research in any way, please tell me. I will try to put things right. If you do not want to speak to me, you can contact Bernie Carter, who is Professor of Children's Nursing and my Director of Studies on 01695 657771 or email bernie.carter@edgehill.ac.uk.

If you would rather speak to someone outside of the research team, you can contact Professor Clare Austin, who is the Associate Dean, Research & Innovation on 01695 650772 or email austincl@edgehill.ac.uk

If you think your child would like to take part in this study and you are happy for them to do this and would like any further information about the study or have any questions, please contact me:

Researcher: Tracy Mitchell

Graduate Teaching Assistant/PhD Studentship, Edge Hill University

01695 650960 or 654353

Tracy.Mitchell@edgehill.ac.uk

Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New Zealand).

Thank you for taking the time to read this information sheet and for considering taking part in this study!

Please keep this information sheet

Appendix 15: Information Sheet for Adults with a Personal Consultee

Edge Hill University

The Life at Home with Medical Equipment Study

Information for Adults with a Personal Consultee

Hello. My name is **Tracy**.

Here is some information about a project I am doing which is exploring what you think of having medical equipment in your home.

Why have I been asked to take part?

I think you can tell me about what having equipment in your home is like.

Do I have to take part?

No! You do not have to take part. No-one will mind if you do not want to.

Who else are you talking to?

People in your family might be taking part as well. I will also be talking to some other children, young people and adults who use medical equipment and their families.

What will happen to me if I say yes, I want to take part?

You can choose to either:

1. **Take some photos about having equipment at home and then talk to me about them.** Someone can help you take the photos if you want. If you live in the North West of England and need a camera, I can lend you one. I will ask you whether I can share your photos and some of the things you say with other people. People might know that you or someone from your family took part in the project when they see the photos, but they will not know what you said. You can tell me which photos I can share and which ones I cannot.

OR

2. **You can just talk to me about having equipment at home.** You do not have to take photos. You can use communication aids if you want or need to. I will either come to your house or talk to you on Skype or telephone. You can have your personal consultee with you when you talk to me if you want to. I will ask you if I can record what you tell me, so that I can remember the important things you say. I will ask whether I can share your some of the things you say about having equipment at home in my work that other people will see. You do not have to say yes. I will not use your real name. You can choose a pretend name for me to use if you want to.

Will anyone else know that I am taking part?

Your personal consultee/the people who you live with will know that you have taken part in the project. I will not tell anyone else that you took part or the things you said unless you tell me something that makes me think that you or other people have been hurt or might get hurt by someone.

What are the good things about taking part?

I hope that you will enjoy taking part in this project. I hope that the things you tell me will help me and other people to understand what living with equipment is like.

What are the bad things about taking part?

I do not think there is anything bad about taking part. You might feel a bit upset talking about the equipment. If this happens I will be kind to you. You can decide if you want to take a break or if you want to stop being in the project.

No one will mind if you say STOP!

Can I change my mind about being part of the project?

Yes! You can change your mind about being in the study and sharing your photos and/or talking to me for up to 7 days from the time of your interview. After this time I will already be using what you told me or showed me in my work. Let your personal consultee know if you change your mind and they can tell me. You can tell me as well!

Did anyone else check the project is OK to do?

Before a project like this can start, a group of people from Edge Hill University meet and read everything to make sure that it is OK to do.

What if I have some questions?

If you or your personal consultee have any questions about the project, please contact me. My contact details are in the box below.

What if I am not happy about this project?

If you are not happy with the project and want to speak to someone else about it, you or your personal consultee can contact Bernie Carter, Professor of Children's Nursing at Edge Hill University on 01695 657771 or bernie.carter@edgehill.ac.uk. Bernie is on my research team.

If you or your personal consultee would prefer to talk to someone outside the research team, you or they can contact Professor Clare Austin who is the Associate Dean, Research & Innovation, on 01695 650772 or email austincl@edgehill.ac.uk.

Researcher: Tracy Mitchell

01695 650960 or 654353
Tracy.Mitchell@edgehill.ac.uk

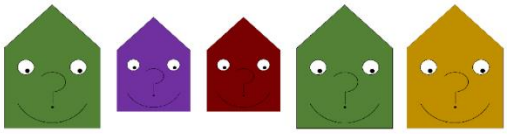
Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New

Thank you for reading this and thinking about my project!

Please keep this information sheet

Appendix 16: Information for Children aged 5-10

Edge Hill University



The Life at Home with Medical Equipment Study

Information for Children aged 5-10

Hello. My name is **Tracy**.

Here is some information about a project I am doing which is exploring what you think of having medical equipment in your home.

Why have I been asked to take part?

I think you can tell me about what having equipment in your home is like. Your mum or dad or carer have said it is OK for you to take part.

Do I have to take part?

No! You do not have to take part. No-one will mind if you do not want to.

Who else are you talking to?

People in your family might be taking part as well. I will also be talking to some other children and their families.

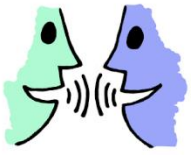
What will happen to me if I say yes, I want to take part?

You can choose to either:

1. **Take some photos about having equipment at home and then talk to me about them.** Someone can help you take the photos if you want. If you need a camera, I can lend you one. I will ask you whether I can share your photos and some of the things you say with other people. You are the boss when it comes to which photos I can share and which ones I cannot.

OR

2. **You can just talk to me about having equipment at home. You do not have** to take photos. You can use communication aids if you want or need to. I will either come to your house to talk to you about the equipment you use at home or talk to you on Skype or telephone. I will ask you whether I can share some of the things you say with other people.



You do not have to say yes. I will not use your real name. You can choose a pretend name for me to use if you want to.

Will anyone else know that I am taking part?

Your mum, dad or carer or other people who you live with will know that you have taken part in the project. I will not tell anyone else that you took part or the things you said unless you tell me something that makes me worried.

What are the good things about taking part?

I hope that you will enjoy taking part in this project. I hope that the things you tell me will help me and other people to understand what living with equipment is like.

What are the bad things about taking part?

I do not think there is anything bad about taking part. You might feel a bit upset talking about the equipment. If this happens I will be kind to you. You can decide if you want to take a break or if you want to stop being in the project.

No one will mind if you say STOP!

Can I change my mind about being part of the project?

Yes! You can change your mind about being in the study and sharing your photos and/or talking to me, or for up to 7 days from the time of your interview. After this time I will already be using what you told me or showed me in my work. Let your mum or dad or carer know if you change your mind and they can tell me. You can tell me as well!

What if I have some questions?

If you have any questions about the project or would like to take part, please tell your mum or dad or carer.

What if I am not happy about this project?

If you are not happy with the project you can tell your mum or dad or carer. They can talk to somebody about this for you.

Researcher: Tracy Mitchell

01695 650960 or 654353
Tracy.Mitchell@edgehill.ac.uk

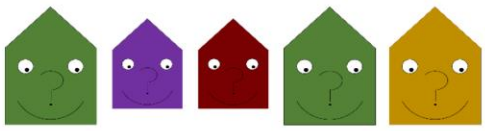
Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New Zealand).

Thank you for reading this and thinking about my project!

Please keep this information sheet

Appendix 17: Information for Personal Consultees

Edge Hill University



The Life at Home with Medical Equipment Study

Information for Personal Consultees

(people who are making the decision as to whether their child aged 16 to 25 years would want to take part in this research study)

My name is **Tracy** and I am responsible for this research study which is exploring how different family members experience medical equipment at home.

I feel that your child/relative is unable to decide for himself/herself whether to take part in this research study or not.

To help decide if he/she should join the study, I would like to ask your opinion whether or not they would want to be involved. I ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your child/relative would have no objection to taking part and you are happy to act as your child's/relative's Personal Consultee, I will ask you to read and sign a Personal Consultee Declaration Form and will provide you with a copy to keep before they participate in the study. It is important that you understand that you are not being asked to consent on behalf of your child/relative. You must set aside any views you may have about the research and consider only the views and interests of your child/relative. I will keep you fully informed during the study so you can let me know if you have any concerns or you think your child/relative should be withdrawn from the study.

If you decide that your child/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of Personal Consultee you may seek independent advice. I will understand if you do not want to take on this responsibility.

If anything is not clear or you need more information, then please feel free to ask me.

The following information is the same as would have been provided to your child/relative.

Why have I been asked to take part?

I think you can tell me about what having equipment in your home is like.

Do I have to take part?

No! You do not have to take part. No-one will mind if you do not want to.

Who else are you talking to?

People in your family might be taking part as well. I will also be talking to some other children, young people and adults who use medical equipment and their families.

What will happen to me if I say yes, I want to take part?

You can choose to either:

1. **Take some photos about having equipment at home and then talk to me about them.** Someone can help you take the photos if you want. If you live in the North West of England and need a camera, I can lend you one. I will ask you whether I can share your photos and some of the things you say with other people. People might know that you or someone from your family took part in the project when they see the photos, but they will not know what you said. You can tell me which photos I can share and which ones I cannot.

OR

2. **You can just talk to me about having equipment at home.** You do not have to take photos. You can use communication aids if you want or need to. I will either come to your house or talk to you on Skype or telephone. You can have your Personal Consultee with you when you talk to me if you want to. I will ask you if I can record what you tell me, so that I can remember the important things you say. I will ask whether I can share your some of the things you say about having equipment at home in my work that other people will see. You do not have to say yes. I will not use your real name. You can choose a pretend name for me to use if you want to.

Will anyone else know that I am taking part?

Your Personal Consultee/the people who you live with will know that you have taken part in the project. I will not tell anyone else that you took part or the things you said unless you tell me something that makes me think that you or other people have been hurt or might get hurt by someone.

What are the good things about taking part?

I hope that you will enjoy taking part in this project. I hope that the things you tell me will help me and other people to understand what living with equipment is like.

What are the bad things about taking part?

I do not think there is anything bad about taking part. You might feel a bit upset talking about the equipment. If this happens I will be kind to you. You can decide if you want to take a break or if you want to stop being in the project.

No one will mind if you say STOP!

Can I change my mind about being part of the project?

Yes! You can change your mind about being in the study and sharing your photos and/or talking to me for up to 7 days from the time of your interview. After this time I will already be using what you told me or showed me in my work. Let your Personal Consultee know if you change your mind and they can tell me. You can tell me as well!

Did anyone else check the project is OK to do?

Before a project like this can start, a group of people from Edge Hill University meet and read everything to make sure that it is OK to do.

What if I have some questions?

If you or your Personal Consultee have any questions about the project, please contact me.

My contact details are in the box below.

What if I am not happy about this project?

If you are not happy with the project and want to speak to someone else about it, you or your Personal Consultee can contact Bernie Carter, Professor of Children's Nursing at Edge Hill University on 01695 657771 or bernie.carter@edgehill.ac.uk. Bernie is on my research team.

If you or your Personal Consultee would prefer to talk to someone outside the research team, you or they can contact Professor Clare Austin who is the Associate Dean, Research & Innovation, on 01695 650772 or email austincl@edgehill.ac.uk.

Researcher: Tracy Mitchell

01695 650960 or 654353

Tracy.Mitchell@edgehill.ac.uk

Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New

Thank you for reading this and thinking about my project!

Please keep this information sheet

Appendix 18: Information for Young People aged 11-15 years

Edge Hill University

The Life at Home with Medical Equipment Study

Information for Young People aged 11-15

Hello. My name is Tracy.
Here is some information about a study I am doing which is exploring what you think of having medical equipment in your home.

Why have I been asked to take part?

You have been asked to take part because I think you can tell me about what having equipment in your home is like. Your mum or dad or carer have said it is OK for you to take part.

Do I have to take part?

No! You do not have to take part. No-one will mind if you do not want to.

Who else are you talking to?

People in your family might be taking part as well. I will also be talking to some other children, young people and young adults and their families.

What will happen to me if I say yes, I want to take part?

You can choose to either:

1. **Take some photos about having equipment at home and then talk to me about them.** Someone can help you take the photos if you want. Please do not take photos that include children or adults outside of the family without their permission If you live in the North West of England and need a camera, I can lend you one. You can share about 15 photos with me if you want to. I will ask you whether I can share your photos with other people. People who know you or your home might know that you or someone from your family took part in the study when they see the photos, but they will not know what you said. You can decide which (if any) photos I can use in my work. I will not include any photos that you are not OK about.

OR

2. **You can just talk to me about having equipment at home.** You do not have to take photos. You can use communication aids if you want or need to. I will either come to your house to talk to you about the equipment you use at home or talk to you on Skype or telephone. You can have your mum or dad or carer with you when you talk to me if you want to. I will ask you if I can record what you tell me so that I can remember the important things you say. I will ask you whether I can share some of the things you say with other people. You do not have to say yes. I will not use your real name. You can make up a name for me to use in the study if you want to.

Will anyone else know that I am taking part?

Your mum, dad or carer or other people who you live with will know that you have taken part in the study. They will not know what you said unless they are with you when you talk to me. I will not tell anyone else that you took part or the things you said unless you tell me something that makes me think that you or other people have been hurt or might get hurt by someone.

What are the good things about taking part?

I hope that you will enjoy taking part in this study. I hope that the things you tell me will help me and other people to understand what living with equipment is like.

What are the bad things about taking part?

I do not think there is anything bad about taking part. You might feel a bit upset talking about the equipment. If this happens I will be kind to you. You can decide if you want to take a break or if you want to stop talking to me or being in the study. No one will mind if you say STOP!

Can I change my mind about being part of the study?

Yes! You can change your mind about sharing your photos or talking to me, or being in the study for up to 7 days from the time of your interview. After this time I will already be using what you told me or showed me in my work. Let your mum or dad or carer know if you change your mind and they can tell me. You can tell me as well!

Did anyone else check the study is OK to do?

Before a study like this can start, a group of people from Edge Hill University meet and read everything to make sure that it is OK to do.

What if I have some questions?

If you have any questions about the study or would like to take part, please talk to your mum or dad or carer and ask them to contact **Tracy**.

What if I am not happy about this study?

If you are not happy with the study and want your mum, dad or carer to speak to someone else about it, they can contact Bernie Carter, Professor of Children's Nursing at Edge Hill University on 01695 657771 or bernie.carter@edgehill.ac.uk. Bernie is on my research team.

If they would prefer to talk to someone outside the research team, they can contact Professor Clare Austin who is the Associate Dean, Research & Innovation, on 01695 650772 or email austincl@edgehill.ac.uk.

Researcher: Tracy Mitchell

01695 650960 or 654353
Tracy.Mitchell@edgehill.ac.uk

Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New Zealand).

Thank you for reading this and thinking about my study!

Please keep this information sheet

Appendix 19: List of Support Organisations

The Life at Home with Medical Equipment Study

List of Support Organisations

Here are the contact details of some support organisations that may be of interest to you:

Together for Short Lives

Together for Short Lives is a charity for parents or carers who look after or know a child or young person who is expected to have a short life. If you have questions or want support, please contact the **Together for Families Helpline free on 0808 8088 100.**

The helpline works on a call-back basis and is open **from 10am until 4pm, Monday-Friday.** Outside of these hours and on Bank Holidays, you can still leave a message on their answerphone and they will return your call as soon as they can when the helpline re-opens.

You can also send an email to: info@togetherforshortlives.org.uk with your helpline query and someone will respond as soon as possible.

The above information was obtained from:
http://www.togetherforshortlives.org.uk/families/helpline

Please ask me for a copy of Together for Short Lives Voices for Families: Advocacy Support Service if you need one.

Rainbow Trust Children's Charity

Rainbow Trust supports any family who has a child aged 0-18 years with a life threatening or terminal illness. They provide bespoke emotional and practical support. Support is given 24/7, for as long as you need it, from the point of diagnosis and beyond. Support for the whole family including parents, carers, the unwell child, brothers, sisters and grandparents at home, in hospital and in the community.

Telephone: 01372 363438 or complete a support request form online at https://rainbowtrust.org.uk/support-for-families/ask-for-support

Also see this link for children: https://rainbowtrust.org.uk/support-for-families/for-children

The above information was obtained from: https://rainbowtrust.org.uk/about/what-we-do

Breathe On UK

Breathe On UK is the independent advocate for all children and young people aged 0-25 who require technology to breathe. Breathe On UK is a national charity supporting the families and carers of young people who are life-dependent on mechanical breathing, or long term ventilation (LTV).

Call on: **01258 820274** or email info@breatheon.org.uk

The above information was obtained from: http://www.breatheon.org.uk/

Scope About Disability

Scope provides support for you at every stage of your child's life, whether your child has a physical impairment, learning disability or any other condition.

Call the free confidential helpline on **0808 800 3333** weekdays 9am -5pm.

Information and disability advice is available for families of children who have just been diagnosed, through to preschool, primary and secondary school children. It also provides disability information in your area.

The above information was obtained from: https://www.scope.org.uk/support/families

National Youth Advocacy Service (NYAS)

The **National Youth Advocacy Service (NYAS)** is a UK charity who offer help, information, advice, advocacy and legal representation to children, young people and vulnerable adults through a network of dedicated paid workers and volunteers throughout England and Wales. They also provide specialist legal advice and assistance.

Call the Freephone helpline on **0808 808 1001** (weekdays 9am-8pm, Saturday 10am-4pm excluding Bank Holidays) or email: help@nyas.net

The above information was obtained from: https://www.nyas.net/

Thank you for taking part in my study!

Researcher: Tracy Mitchell

01695 650960 or 654353

Tracy.Mitchell@edgehill.ac.uk

Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New Zealand).

Voices for Families: Advocacy Support Service

Assisting | Supporting | Advocating

Do you need free advice on any of the following issues:

- Welfare benefits, allowances, personal budgets or money?
- Assessments and care plans for your child?
- Housing, adaptations, including suitability of your accommodation?
- Employment disputes, including flexible working around your child?
- Transition to adult services?

If you are a parent of a child with a life-limiting condition or an affected young person, we can provide you with a volunteer support advocate to assist you and your family through some of the problems you're facing, acting on your behalf to help you get the support you need.

To speak with someone about how to access advocacy support contact the Together for Short Lives Helpline on 0808 8088 100.

Voices for Families is a partnership between LawWorks, the national pro bono group for solicitors and Together for Short Lives, the UK charity representing all children and young people with a life-limiting condition and their families as well as the organisations and people that support them. We are also piloting drop in clinics providing free advice for families at a number of children's hospices and other children's palliative care organisations – contact us for more information.

"Words can't describe the impact the Voices for Families support project has had on my family. All that has been achieved has been through the hard work and tireless dedication the support advocates provided. They have been a blessing to my family..."

www.togetherforshortlives.org.uk

Appendix 20: Adult Consenting for a Child Consent Form

Edge Hill University

Adult Consenting for a Child or Young Person aged 5 – 15 years

The Life at Home with Medical Equipment Study **Name of researcher: Tracy Mitchell**	**Please initial box**
I confirm that I have read and explained the relevant information sheet/s for the above study to my child and that we have had the opportunity to ask questions: (Tracy will cross out those that are not appropriate) • **Information for Children aged 5-10** (Info Sheet - Child Age 5-10 Life @ Home Med Equip. V3. 22.3.18) • **Information for Young People aged 11-15** (Info Sheet – Young People Age 11-15 Life @ Home Med Equip. V3. 22.3.18) • **Information for Adults Consenting for Children or Young People** (Info Sheet – Adults Consenting for CYP aged 5-15. Life @ Home Med Equip. V3. 22.3.18)	
I understand that my child's participation is voluntary and that they are free to withdraw up to 7 days after the interview, without giving any reason and without their legal rights being affected.	
I understand that my child's interview will be audio recorded with their permission and that their anonymised interview transcript will be stored securely by Tracy in a locked drawer or password protected computer to form part of the data collection for this study. I agree for this to happen.	
I understand that some of the things that my child says in the interview may be quoted anonymously in Tracy's PhD thesis, and future publications or presentations. I agree for this to happen.	
I give permission for my child's anonymised transcripts to be kept for use in Tracy's and her supervisors future studies.	
I understand that the data collected during the study may be looked at by individuals from Tracy's supervisory team or regulatory authorities. I give permission for these individuals to have access to the records.	
I agree for my child to take part in the above study if they want to.	
I understand that the photographs that my child shares with Tracy will form part of the data collection for this study and will be stored securely in a locked drawer or password protected computer. I agree for this to happen.	
I understand the risk that the photographs that my child gives Tracy permission to use in her PhD thesis, publications and presentations could lead to someone who sees the photos knowing that my child or someone from my family has taken part in the study.	
I understand that my child and I will decide which photographs to share with Tracy and that we can ask Tracy to edit out identifying information.	
I understand that Tracy will only include photos that we are OK with being used and she will safely destroy any photos that we do not give consent to be retained as part of the research study.	
I give permission for my child's photographs to be kept for use in Tracy's and her supervisors' future studies.	

Name of Child _____ **Date** _____ **Name of Parent/Guardian & Signature** _____

Pretend Name _____

Name of Researcher _____ **Date** _____ **Signature** _____

Appendix 21: Adult Consent Form

Edge Hill University

Adult Consent Form

The Life at Home with Medical Equipment Study **Name of researcher: Tracy Mitchell**	**Please initial box**
I confirm that I have read and understand the **Information for Adults** sheet (*Info Sheet – Adult. Life @ Home Med Equip. V3. 22.3.18)* for the above study and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time up to 7 days after the interview, without giving any reason and without my legal rights being affected.	
I understand that the interview will be audio recorded with my permission and that the recording and interview transcript will be stored securely by Tracy to form part of the data collection for this study. I agree for this to happen.	
I understand that the things I say to Tracy in the interview will be anonymised and may be quoted in her PhD thesis and any future publications or presentations. I agree for this to happen.	
I give permission for my anonymised transcripts to be kept for use in Tracy's and her supervisors' future studies.	
I understand that the data collected during the study may be looked at by individuals from Tracy's supervisory team or from regulatory authorities. I give permission for these individuals to have access to the records.	
I agree to take part in the study.	
I understand that the photos I share with Tracy will form part of the data collection for this study and will be stored securely in a locked drawer or password protected computer. I agree for this to happen.	
I understand the risk that the photos that I give Tracy permission to use in her PhD thesis, presentations or publications could lead to someone who sees the photos knowing that I, or someone from my family, has taken part in the study.	
I understand that I will decide which photos to share with Tracy and that I can ask Tracy to edit out identifying information from them.	
I understand that Tracy will only include photos that I am OK with being used and she will safely destroy any photos that I do not give consent to be retained as part of the research study.	
I give permission for my photos to be kept for use in Tracy's and her supervisors' future studies.	

Name of Participant	**Date**	**Signature**
Name of Researcher	**Date**	**Signature**

Participant ID Number:

Consent Form - Adult. Life @ Home Med Equip. V3. 22.3.18

Appendix 22: Adults who have a Personal Consultee Consent Form

Edge Hill University

Consent Form
Adults who have a Personal Consultee

The Life at Home with Medical Equipment Study **Name of person doing the study: Tracy Mitchell**	**Please tick, make a mark on or initial box (or say Yes) if you agree.**
I have read the **Information for Adults who have a Personal Consultee** sheet (V1. 25.5.17) (with help from my mum/dad/carer and Tracy if I needed it). I have asked questions if I needed to.	
I know that I do not have to take part and can change my mind about being part of Tracy's study up to 7 days after talking to Tracy about the equipment. I will tell my mum/dad/carer if I want to stop being part of the study so that they can tell Tracy.	
I know that I can say yes or no to Tracy recording what I say in the interview and that Tracy will take care of what I told her.	
I know that Tracy will write some of the things I say in her report and other documents or presentations and that other people will read this. I know that Tracy will not use my real name in these.	
The typed document of what I say to Tracy during the interview (which will not have my real name or places in it) can be used in Tracy's and her supervisors' future studies.	Yes or No
I know that some information from this study may have to be looked at by people who check the research is done properly.	
I want to take part in this study.	Yes or No
I know that Tracy will keep my photos in a locked drawer or on a computer with a password that no one except Tracy knows. I agree for this to happen.	
I know that if people who know me or my family see my photos in Tracy's report and other documents or presentations that they might know that I or a member of my family took part in the study.	
I know that I can tell Tracy which photos I want her to take something out of or change.	
I know that I can tell Tracy which photos she can use and which she cannot. I know that Tracy will not use any photos that my family and I are not OK about.	
My photos can be used in Tracy's and her supervisors' future studies.	Yes or No

Name of Participant	**Date**	**Signature**
Name of Researcher	**Date**	**Signature**

Pretend name chosen: ……..

Appendix 23: Child Assent Form

Edge Hill University

Child Assent Form aged 5-10

The Life at Home with Medical Equipment Study **Name of person doing the study: Tracy Mitchell**	**Please tick, make a mark on or initial box (or say Yes) if you agree.**
I have read the **Information for Children aged 5-10** sheet (V3. 22.3.18) (with help from my mum/dad/carer if I needed it). I have asked questions if I needed to.	
I know that I do not have to take part and can change my mind about what I say being part of Tracy's study up to 7 days after talking to Tracy about the equipment. I will tell my mum/dad/carer if I want to stop being part of the study so that they can tell Tracy.	
I know that I can say yes or no to Tracy recording what I say in the interview and that Tracy will take care of what I told her.	
I know that Tracy will write some of the things I say in her report and other documents or presentations and that other people will read this. I know that Tracy will not use my real name in these.	
The typed document of what I say to Tracy during the interview (which will not have my real name or places in it) can be used in Tracy's and her supervisors' future studies.	Yes or No
I know that some information from this study may have to be looked at by people who check the research is done properly.	
I want to take part in this study.	Yes or No
I know that I can change my mind about my photos being part of Tracy's study up to 7 days after talking to Tracy about the equipment. I will tell my mum/dad/carer if I want to stop my photos being part of the study so that they can tell Tracy.	
I know that Tracy will look after my photos very carefully by locking them in a drawer or on a computer with a password that no one except Tracy knows. I agree for this to happen.	
I know that if people who know me or my family see my photos in Tracy's report and other documents or presentations that they might know that I, or a member of my family, took part in the study.	
I know that I can tell Tracy which photos she can use and which she cannot. I know that Tracy will not use any photos that my family and I are not OK about.	
I know that I can tell Tracy which photos I want her to take something out of or change.	
My photos can be used in Tracy's and her supervisors' future studies.	Yes or No

Name of Participant	**Date**	**Signature**
Name of Researcher	**Date**	**Signature**

Pretend name chosen: ……..

Participant ID Number: Consent Form – Child 5-10 Assent Form. Life @ Home Med Equip. V3 22.3.18

Appendix 24: Young Person Assent Form

Edge Hill University

Young People Assent Form aged 11-15

The Life at Home with Medical Equipment Study **Name of researcher: Tracy Mitchell**	**Please tick, make a mark on or initial box (or say Yes).**
I have read the **Information for Young People aged 11-15** sheet (V3. 22.3.18) (with help from my mum/dad/carer if I needed it). I have asked questions if I needed to.	
I know that I do not have to take part.	
I know that I can change my mind about what I say being part of the study up to 7 days after talking to Tracy in the interview. I will tell my mum/dad/carer if I want to stop being part of the study so that they can contact Tracy to tell her.	
I know that I can say yes or no to Tracy recording what I say in the interview and that Tracy will look after what I said very carefully, in a locked drawer or on a computer with a password that no one except Tracy knows. I agree for this to happen.	Yes or No
I know that Tracy will write some of the things I say in her report and other documents or presentations and that other people will read this. I know that Tracy will not use my real name in these.	
The typed document of what I say to Tracy during the interview (which will not have my real name or places in it) can be used in Tracy's and her supervisors' future studies.	Yes or No
I know that some information from this study may have to be looked at by people who check the research is done properly.	
I want to take part in this study.	Yes or No
I know that I can change my mind about my photos being part of Tracy's study up to 7 days after talking to Tracy about the equipment. I will tell my mum/dad/carer if I want to stop my photos being part of the study so that they can tell Tracy.	
I know that Tracy will look after my photos very carefully by locking them in a drawer or on a computer with a password that no one except Tracy knows. I agree for this to happen.	
I know that if people who know me or my family see my photos in Tracy's report and other documents or presentations that they might know that I, or a member of my family, took part in the study.	
I know that I can tell Tracy which photos she can use and which she cannot. I know that Tracy will not use any photos that my family and I are not OK about.	
I know that I can tell Tracy which photos I want her to change or take something out of.	
My photos can be used in Tracy's and her supervisors' future studies.	Yes or No

Name of Participant	**Date**	**Signature**
Name of Researcher	**Date**	**Signature**

Pretend name chosen: ……..

Participant ID Number:

Appendix 25: Personal Consultee Declaration Form

Edge Hill University

Personal Consultee Declaration Form

The Life at Home with Medical Equipment Study **Name of researcher: Tracy Mitchell**	**Please initial or N/A box**
I confirm that I have been consulted about my child ……..'s participation in this research project.	
I confirm that I have read and understand the **Information for Personal Consultees** sheet (Info Sheet – Personal Consultee. Life @ Home Med Equip. V2. 22.3.18) for the above study and have had the opportunity to ask questions and understand what is involved.	
I understand that my child's participation is voluntary and that they and/or I can request that he/she is withdrawn from the study at any time up to 7 days after the interview, without giving any reason and without his/her care or legal rights being affected.	
In my opinion, my child would give their permission for the interview to be audio recorded and would agree to the recording and interview transcript being stored securely by Tracy to form part of the data collection for this study.	
In my opinion, my child would give their permission for the things they say to Tracy in the interview to be anonymised and quoted in Tracy's PhD thesis and any future publications or presentations.	
In my opinion, my child would give their permission for their anonymised transcripts to be kept for use in Tracy's and her supervisors' future studies.	
In my opinion, my child would give permission for the data collected during the study to be looked at by individuals from Tracy's supervisory team or from regulatory authorities.	
In my opinion, my child would have no objection to taking part in this study.	
In my opinion, my child would agree for the photos that they share with Tracy to be stored securely in a locked drawer or on a password protected computer and to form part of the data collection for this study.	
I believe that my child would give Tracy permission to use the photos that they share with her in her PhD thesis, presentations or publications, even though there is a risk that the photos could lead to someone who sees them knowing that my child or someone from our family has taken part in the study.	
I confirm that I will support my child's wishes, feelings and interests to ask Tracy to edit out identifying information from photos.	
My child knows that Tracy will only include photos that they are OK with being used and will destroy any photos that she does not have permission to be retained as part of the research study.	
In my opinion, my child would give their permission for their photos to be kept for use in Tracy's and her supervisors' future studies.	

Name of Personal Consultee	**Date**	**Signature**
Name of Researcher	**Date**	**Signature**

Participant ID Number: Personal Consultee Declaration Form. Life @ Home Med Equip. V2. 22.3.18

Appendix 26: Interview Schedule for Children aged 5-10 years

Edge Hill University

The Life at Home with Medical Equipment Study

INTERVIEW STRUCTURE FOR CHILDREN AGED 5-10

***Research Question**: How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*

The questions asked at the interview will be triggered and guided by the photographs that each child has taken and the photographs that the child chooses to talk about. It is difficult to provide an exact interview schedule but the interview structure will be something like the following:

Introductions and Explanations:

- **Reminding child who I am and what the study is about**
- **Thanking child for taking part** (Note focus will shift depending on whether the child is dependent on technology or the brother or sister of a child who is dependent on technology).
- **Revisiting the information sheet and confirming child's ongoing assent and gaining permissions to record the interview.**
- **Explaining that it is OK to pause the interview, move onto another question, end the interview or rearrange it for another day.**
- **Once assent and understanding of recording is ascertained the interview will proceed.**

Interview:

Gathering some **demographic details:**

- Family composition – Who lives here with you?
- Do you have any brothers or sisters (or other children) who live with you? (younger/older?)
- Who looks after you/your brother/sister? (in your home or their home?)

Ask child to share their photographs (if taken) Note: I will be trying to elicit a story linked to the photograph. Prompts around the photos will be used only if necessary. Questions will be guided by the child's responses but are likely to proceed as follows:

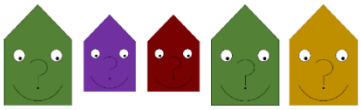
- I asked you to take some photographs about living with equipment. Please can I look at them with you? Shall we spread them out so you can see them all?
- Which picture do you want to talk about first/next? (Why do you want to talk about this photo? What is important about this photo? What (or who) is in this photo?)

Prompts as to experience of medical equipment in the home

- What's happening in this photo? How do you feel about this? Does having equipment make a difference to what's happening in this photo? Which equipment do you like the most/least, why etc.? Do you get upset about any of the equipment? Please can you tell me more about this/I don't know about that can you tell me about it…). Was the equipment harder to live with during the earlier months/years?

Prompts as to whether and how the fabric of the home is changed

- Is your home the same or a bit different to your friends' home(s)? How? Where is the equipment kept? Do you get to make decisions about this? Are there any rooms that you are not allowed to go in? Do your friends come round to play/sleep over? If the child is tech-dep – Do you go and play/sleep over at your friends/relatives' house? (prompts around the child's response – if no, is this because of the equipment being too big, too specialised, irreplaceable etc.?)



Anything Else?

Endings:

Would you like to choose a pretend name for me to use in my written work that other people will see?

Check which photos the child is fully happy to share/which require editing. Support the transfer of photos to me as necessary (confirming that consenting adult is happy for the child to share these).

Check that the child is OK.

Provide support organisations information leaflet to parents as required.

Thank child for taking part.

Questions will broadly focus on:

1. *How the child experiences medical technology in the home.*
2. *Whether and how the fabric of the home is changed.*
3. *Whether any practices facilitate the integration of technology into the home (less so for child interviews).*

Appendix 27: Interview Schedule for Adults

Edge Hill University

The Life at Home with Medical Equipment Study

INTERVIEW STRUCTURE FOR ADULTS (PARENTS/RELATIVES/CARERS)

***Research Question**: How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*

The questions asked at the interview will be triggered and guided by the photographs that each participant has taken and the photographs that the participant chooses to talk about. It is difficult to provide an exact interview schedule but the interview structure will be something like the following:

Introductions and Explanations:

- **Reminding participant who I am and what the study is about**
- **Thanking participant for taking part**.
- **Revisiting the information sheet and confirming participant's ongoing assent and gaining permissions to record the interview.**
- **Explaining that it is ok to pause the interview, move onto another question, end the interview or rearrange it for another day.**
- **Once consent and understanding of recording is ascertained the interview will proceed.**

Interview:

Gathering some **demographic details:**

- Family composition – Who lives here with you?
- How long have you lived here?
- Have you always lived here – if you moved was it related to your child's/grandchild's/sibling's/other relative's equipment?
- Do your child/grandchild etc. have any brothers or sisters? (birth order - younger/older?)
- How long has your child etc. relied upon equipment to keep them healthy?
- Are there any family members who support your child's care in your home or their home?

Ask participant to share their photographs (if taken) Note: I will be trying to elicit a story linked to the photograph. Prompts around the photos will be used only if necessary. Questions will be guided by the participant's responses but are likely to proceed as follows:

- I asked you to take some photographs about living with equipment. Please can I look at them with you?
- Which picture do you want to talk about first/next? (Why do you want to talk about this photo? What is important about this photo? What (or who) is in this photo?)

Experience of Medical Equipment in the Home

- What's happening in this photo?
- Please can you tell me about each piece of technology?
- What does it do?
- How do you feel about this?
- Does having equipment make a difference to what's happening in this photo?
- Please tell me about that piece of equipment
- Has your life /your family's life been changed by the equipment? If so, how? [good/bad etc.]
- What are the main challenges of having this equipment at home?
- What are the benefits of living with equipment at home?
- Which equipment do you like the most/least? Why etc.?
- Do you get upset about any of the equipment?
- Please can you tell me more about this/I don't know about that can you tell me about it…

- Was the equipment harder to live with during the earlier months?
- Has having the equipment prevented you from moving house?

Whether and How the Fabric of the Home is Changed

- Has your home/rooms in your home been changed by the equipment? If so, what's different/how? Are rooms used differently now?
- Does having equipment in your home create limits/constraints for you/your family/guests? Do you have guests visit or stay over? Are there rooms that are out of bounds?
- Has the equipment changed the home over time - Are there any changes as your child etc. has grown up (physically bigger and heavier)?
- Is your child etc. able to go and stay over at your relatives' or friends' houses? (prompts around the participant's response – if no, is this because of the equipment being too big, too specialised, irreplaceable etc.?)

Whether any Practices Facilitate the Integration of Equipment into the Home

- If you had a chance to influence someone designing the equipment what key thing would you like them to take notice of?
- Where is the equipment kept/stored? (what is good/bad about this?)
- Has anything helped with integrating the equipment into your home? (e.g. the practices around the installation of the equipment; the design/size of the equipment; someone to coordinate the supply and delivery of the equipment; the frequency of delivery;).

Anything Else?

Endings:

Would you like to choose a pseudonym for me to use in documentation and presentations?

Check which photos the participant is fully happy to share/which require editing. Support the transfer of photos to me as necessary.

Check that participant is ok.

Provide list of support organisations.

Thank participant for taking part.

Questions will broadly focus on:

1. *How the participant experiences medical technology in the home.*
2. *Whether and how the fabric of the home is changed.*
3. *Whether any practices facilitate the integration of technology into the home.*

Appendix 28: Interview Schedule for Adults who have a Consultee

Edge Hill University

The Life at Home with Medical Equipment Study

INTERVIEW STRUCTURE FOR ADULTS WHO HAVE A CONSULTEE

***Research Question**: How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*

The questions asked at the interview will be triggered and guided by the photographs (or equipment, if photographs have not been taken) that each participant has taken and the photographs (equipment) that the participant chooses to talk about. It is difficult to provide an exact interview schedule but the interview structure will be something like the following:

Introductions and Explanations:

- **Reminding participant who I am and what the study is about**
- **Thanking participant for taking part** (Note focus will shift depending on whether the participant is dependent on technology or the brother or sister of a participant who is dependent on technology).
- **Revisiting the information sheet and confirming participant's consent and gaining permissions to record the interview, referring to Consultee as necessary.**
- **Explaining that it is OK to pause the interview, move onto another question, end the interview or rearrange it for another day.**
- **Once consent/Consultee Declaration is gained and understanding of recording is ascertained the interview will proceed.**

Interview:

Gathering some **demographic details:**

- Family composition – Who lives here with you?
- Do you have any brothers or sisters (or other children) who live with you? (younger/older?)
- Who looks after you/your brother/sister? (in your home or their home?)

Ask participant to share their photographs (if taken) Note: I will be trying to elicit a story linked to the photograph. Prompts around the photos will be used only if necessary. Questions will be guided by the participant's responses but are likely to proceed as follows:

- I asked you to take some photographs about living with equipment. Please can I look at them with you? Shall we spread them out so you can see them all?
- Which picture (equipment) do you want to talk about first/next? (Why do you want to talk about this photo? What is important about this photo? What (or who) is in this photo?)

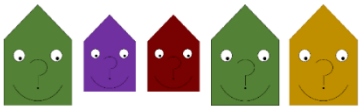
Prompts as to experience of medical equipment in the home

- What's happening in this photo (if taken)? How do you feel about this? Does having equipment make a difference to what's happening in this photo? Which equipment do you like the most/least, why etc.? Do you get upset about any of the equipment? Please can you tell me more about this/I don't know about that, can you tell me about it…Was the equipment harder to live with at first?

Prompts as to whether and how the fabric of the home is changed

- Is your home the same or a bit different to your friends' home(s)? How? Where is the equipment kept? Do you get to make decisions about this? Do you go and stay over at your friends/relatives' house? (prompts around the participant's response – if no, is this because of the equipment being too big, too specialised, irreplaceable etc.?)

Anything Else?



Endings:

Would you like to choose a pretend name for me to use in my written work that other people will see?

Check which photos the participant is fully happy to share/which require editing, referring to Consultee as necessary. Support the transfer of photos to me as necessary.

Check that the participant is OK.

Provide list of support organisations.

Thank participant for taking part.

Questions will broadly focus on:

1. *How the participant experiences medical technology in the home.*
2. *Whether and how the fabric of the home is changed.*
3. *Whether any practices facilitate the integration of technology into the home.*

Appendix 29: Interview Schedule for Adults who rely on Technology

Edge Hill University

The Life at Home with Medical Equipment Study

INTERVIEW STRUCTURE FOR ADULTS WHO RELY ON TECHNOLOGY

***Research Question**: How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*

The questions asked at the interview will be triggered and guided by the photographs (or the equipment, if the participant hasn't taken photographs) that each participant has taken and the photographs (equipment) that the participant chooses to talk about. It is difficult to provide an exact interview schedule but the interview structure will be something like the following:

Introductions and Explanations:

- **Reminding participant who I am and what the study is about**
- **Thanking participant for taking part**.
- **Revisiting the information sheet and confirming participant's ongoing assent and gaining permissions to record the interview.**
- **Explaining that it is ok to pause the interview, move onto another question, end the interview or rearrange it for another day.**
- **Once consent and understanding of recording is ascertained the interview will proceed.**

Interview:

Gathering some **demographic details:**

- Family composition – Who lives here with you?
- How long have you lived here?
- Have you always lived here – if you moved was it related to your equipment?
- Do you have any brothers or sisters? (younger/older?)
- How long have you relied upon equipment to keep you healthy?
- Are there any family members who do not live with you but who also support care in your home?

Ask participant to share their photographs (if taken) Note: I will be trying to elicit a story linked to the photograph. Prompts around the photos will be used only if necessary. Questions will be guided by the participant's responses but are likely to proceed as follows:

- I asked you to take some photographs about living with equipment. Please can I look at them with you?
- Which picture do you want to talk about first/next? (Why do you want to talk about this photo? What is important about this photo? What (or who) is in this photo?)

Experience of Medical Equipment in the Home

- What's happening in this photo?
- How do you feel about this?
- Does having equipment make a difference to what's happening in this photo?
- Please tell me about that piece of equipment
- Has your life /your family's life been changed by the equipment? If so, how? [good/bad etc.]
- What are the main challenges of having this equipment at home?
- What are the benefits of living with equipment at home?
- Which equipment do you like the most/least? Why etc.?
- Do you get upset about any of the equipment?
- Please can you tell me more about this/I don't know about that can you tell me about it…
- Was the equipment harder to live with during the earlier months?
- Has having the equipment prevented you from moving house?

Whether and How the Fabric of the Home is Changed

- Has your home/rooms in your home been changed by the equipment? If so, what's different / how?
- Is your home the same or a bit different to your friends' home(s)? How?
- Does having equipment in your home create limits/constraints for you/your family/guests

- Has the equipment changed the home over time - Are there any changes as you have grown up (physically bigger and heavier)?
- Do you go and stay over at your friends/relatives' house? (prompts around the participant's response – if no, is this because of the equipment being too big, too specialised, irreplaceable etc.?)

Whether any Practices Facilitate the Integration of Equipment into the Home

- If you had a chance to influence someone designing your equipment what key thing would you like them to take notice of?
- Where is your equipment kept/stored? (what is good/bad about this?)
- Has anything helped with integrating the equipment into your home? (e.g. the practices around the installation of the equipment; the design/size of the equipment; someone to coordinate the supply and delivery of the equipment; the frequency of delivery).

Anything Else?

Endings:

Would you like to choose a pseudonym for me to use in documentation and presentations?

Check which photos the participant is fully happy to share/which require editing. Support the transfer of photos to me as necessary.

Check that participant is ok.

Provide list of support organisations.

Thank participant for taking part.

Questions will broadly focus on:

1. *How the participant experiences medical technology in the home.*
2. *Whether and how the fabric of the home is changed.*
3. *Whether any practices facilitate the integration of technology into the home.*

Appendix 30: Interview Schedule for Young People aged 11-15 years

Edge Hill University

The Life at Home with Medical Equipment Study

INTERVIEW STRUCTURE FOR YOUNG PEOPLE AGED 11-15

***Research Question**: How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*

The questions asked at the interview will be triggered and guided by the photographs that each young person has taken and the photographs that the young person chooses to talk about. It is difficult to provide an exact interview schedule but the interview structure will be something like the following:

Introductions and Explanations:

- **Reminding young person who I am and what the study is about**
- **Thanking young person for taking part** (Note focus will shift depending on whether the young person is dependent on technology or the brother or sister of a child who is dependent on technology).
- **Revisiting the information sheet and confirming young person's ongoing assent and gaining permissions to record the interview.**
- **Explaining that it is OK to pause the interview, move onto another question, end the interview or rearrange it for another day.**
- **Once assent and understanding of recording is ascertained the interview will proceed.**

Interview:

Gathering some **demographic details:**

- Family composition – Who lives here with you?
- If there are brothers or sisters (or other children) are they younger/older?
- Who looks after you/your brother/sister? (in your home or their home?)

Ask young person to share their photographs (if taken) Note: I will be trying to elicit a story linked to the photograph. Prompts around the photos will be used only if necessary. Questions will be guided by the young person's responses but are likely to proceed as follows:

- I asked you to take some photographs about living with equipment. Please can I look at them with you? Shall we spread them out so you can see them all?
- Which picture do you want to talk about first/next? (Why do you want to talk about this photo? What is important about this photo? What (or who) is in this photo?)

Prompts as to experience of medical equipment in the home

- What's happening in this photo? How do you feel about this? Does having equipment make a difference to what's happening in this photo? Has your life /your family's life been changed by the equipment? If so, how? [good/bad etc.] Which equipment do you like the most/least, why etc.? Do you get upset about any of the equipment? Please can you tell me more about this/I don't know about that can you tell me about it…) Was the equipment harder to live with during the earlier months?

Prompts as to whether and how the fabric of the home is changed

- Is your home the same or a bit different to your friends' home(s)? How? Where is the equipment kept? Do you get to make decisions about this? Do your friends come to your house/sleep over? Are there any rooms that you and your friends do not/are not allowed to go in? If the young person is tech-dep – Do you go round to or sleep over at your

friends/relatives' houses? (prompts around the young person's response – if no, is this because of the equipment being too big, too specialised, irreplaceable etc.?)

Whether any Practices Facilitate the Integration of Equipment into the Home

- If you had a chance to influence someone designing your equipment what key thing would you like them to take notice of?
- Where is your equipment kept/stored? (what is good/bad about this?)

Anything Else?

Endings:

Would you like to choose a pretend name for me to use in my report and other publications and presentations that other people will see?

Check which photos the young person is fully happy to share/which require editing. Support the transfer of photos to me as necessary (confirming that consenting adult is happy for the child to share these).

Check that the young person is OK.

Provide support organisation details as required.

Thank young person for taking part.

Questions will broadly focus on:

1. *How the young person experiences medical technology in the home.*
2. *Whether and how the fabric of the home is changed.*
3. *Whether any practices facilitate the integration of technology into the home (less so for young person interviews).*

Appendix 31: Faculty Research Ethics Committee Approval June 2017

Edge Hill University

Tracy Mitchell

27th June 2017

Dear Tracy,

Thank you for submitting your research ethics application '*How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*' (FOHS 171) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to the HRA for approval for the research to be conducted in the NHS. All NHS R&D departments (in Trusts where data is being collected) will also need to be approached for Trust permission to proceed.

3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study

4. The Principle Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

5. The Principle Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator (browdan@edgehill.ac.uk). The form will be sent to you at the appropriate time by the Committee Administrator.

6. Ethical approval for this research will expire on 31/08/2019. Any extensions to this date will require additional approval from the committee.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	**<version no & date>**

Consent Form – Adult Consenting for CYP age 5-15 yrs	**V2, 25/05/2017**
Consent Form – Adult	**V2, 25/05/2017**
Consent Form – Adult with a Personal Consultee	**V1, 25/05/2017**
Consent Form – Child 5-10 Assent Form	**V2, 25/05/2017**
Consent Form – YP 11-15 Assent Form	**V2, 25/05/2017**
Consultee (Personal) Declaration Form Life	**V1, 25/05/2017**
Flyer	**V2, 25/05/2017**
Info Sheet – Adults	**V2, 25/05/2017**
Info Sheet – Adults Consenting for CYP aged 5-15	**V2, 25/05/2017**
Info Sheet – Adults with a Personal Consultee	**V1, 25/05/2017**
Info Sheet – Child Age 5-10	**V2, 25/05/2017**
Info Sheet – Personal Consultee	**V1, 25/05/2017**
Info Sheet – Support Organisations	**V1, 30/03/2017**
Info Sheet – Young People 11-15	**V2, 25/05/2017**
Interview Structure Children aged 5-10	**V1, 30/03/2017**
Interview Structure. Adults (Parents, Relatives, Carers)	**V1, 30/03/2017**
Interview Structure. Adults who have a Consultee	**V1, 25/05/2017**
Interview Structure. Adults who rely on Tech	**V1, 30/03/2017**
Interview Structure. Young People aged 11-15	**V1, 30/03/2017**
Invitation Letter	**V2, 25/05/2017**
Faculty Proposal Template	**V2, 25/05/2017**

Yours sincerely

Professor Mary O'Brien

Chair of Faculty of Health & Social Care Research Ethics Committee
Edge Hill University
St Helens Road
Ormskirk
Lancashire
L39 4QP
obrienm@edgehill.ac.uk

Appendix 32: Faculty Research Ethics Committee Approval August 2017

Edge Hill University

Tracy Mitchell

4th August 2017

Dear Tracy,

Thank you for submitting your amended research ethics application '*How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*' (FOHS 171) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to the HRA for approval for the research to be conducted in the NHS. All NHS R&D departments (in Trusts where data is being collected) will also need to be approached for Trust permission to proceed.

3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study

4. The Principle Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

5. The Principle Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator (browdan@edgehill.ac.uk). The form will be sent to you at the appropriate time by the Committee Administrator.

6. Ethical approval for this research will expire on 31/08/2019. Any extensions to this date will require additional approval from the committee.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	**<version no & date>**

Consent Form – Adult Consenting for CYP age 5-15 yrs	**V2, 25/05/2017**
Consent Form – Adult	**V2, 25/05/2017**
Consent Form – Adult with a Personal Consultee	**V1, 25/05/2017**
Consent Form – Child 5-10 Assent Form	**V2, 25/05/2017**
Consent Form – YP 11-15 Assent Form	**V2, 25/05/2017**
Consultee (Personal) Declaration Form Life	**V1, 25/05/2017**
Flyer	**V2, 25/05/2017**
Info Sheet – Adults	**V2, 25/05/2017**
Info Sheet – Adults Consenting for CYP aged 5-15	**V2, 25/05/2017**
Info Sheet – Adults with a Personal Consultee	**V1, 25/05/2017**
Info Sheet – Child Age 5-10	**V2, 25/05/2017**
Info Sheet – Personal Consultee	**V1, 25/05/2017**
Info Sheet – Support Organisations	**V1, 30/03/2017**
Info Sheet – Young People 11-15	**V2, 25/05/2017**
Interview Structure Children aged 5-10	**V1, 30/03/2017**
Interview Structure. Adults (Parents, Relatives, Carers)	**V1, 30/03/2017**
Interview Structure. Adults who have a Consultee	**V1, 25/05/2017**
Interview Structure. Adults who rely on Tech	**V1, 30/03/2017**
Interview Structure. Young People aged 11-15	**V1, 30/03/2017**
Invitation Letter	**V2, 25/05/2017**
Faculty Proposal Template	**V3, 03/08/2017**

Yours sincerely

Professor Mary O'Brien

Chair of Faculty of Health & Social Care Research Ethics Committee
Edge Hill University
St Helens Road
Ormskirk
Lancashire
L39 4QP
obrienm@edgehill.ac.uk

Appendix 33: Faculty Research Ethics Committee Approval March 2018

Edge Hill University

Tracy Mitchell

28th March 2018

Dear Tracy,

Thank you for submitting your amended research ethics application '*How does medical technology affect life at home for children, young people and young adults with complex healthcare needs and their families?*' (FOHS 171) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to the HRA for approval for the research to be conducted in the NHS. All NHS R&D departments (in Trusts where data is being collected) will also need to be approached for Trust permission to proceed.

3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study

4. The Principal Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

5. The Principal Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator (browdan@edgehill.ac.uk). The form will be sent to you at the appropriate time by the Committee Administrator.

6. Ethical approval for this research will expire on 31/08/2019. Any extensions to this date will require additional approval from the committee.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	**<version no & date>**

Consent Form – Adult Consenting for CYP age 5-15 yrs	**V3, 22/03/2018**
Consent Form – Adult	**V3, 22/03/2018**
Consent Form – Adult with a Personal Consultee	**V1, 25/05/2017**
Consent Form – Child 5-10 Assent Form	**V3, 22/03/2018**
Consent Form – YP 11-15 Assent Form	**V3, 22/03/2018**
Consultee (Personal) Declaration Form Life	**V2, 22/03/2018**
Flyer	**V3, 22/03/2018**
Info Sheet – Adults	**V3, 22/03/2018**
Info Sheet – Adults Consenting for CYP aged 5-15	**V3, 22/03/2018**
Info Sheet – Adults with a Personal Consultee	**V1, 25/05/2017**
Info Sheet – Child Age 5-10	**V3, 22/03/2018**
Info Sheet – Personal Consultee	**V2, 22/03/2018**
Info Sheet – Support Organisations	**V1, 30/03/2017**
Info Sheet – Young People 11-15	**V3, 22/03/2018**
Interview Structure Children aged 5-10	**V1, 30/03/2017**
Interview Structure. Adults (Parents, Relatives, Carers)	**V1, 30/03/2017**
Interview Structure. Adults who have a Consultee	**V1, 25/05/2017**
Interview Structure. Adults who rely on Tech	**V1, 30/03/2017**
Interview Structure. Young People aged 11-15	**V1, 30/03/2017**
Invitation Letter	**V2, 25/05/2017**
Faculty Proposal Template	**V4, 22/03/2018**

Yours sincerely

Mary Robrien

Professor Mary O'Brien

Chair of Faculty of Health & Social Care Research Ethics Committee
Edge Hill University
St Helens Road
Ormskirk
Lancashire
L39 4QP
obrienm@edgehill.ac.uk

Appendix 34: General Data Protection Regulation Statement

The Life at Home with Medical Equipment Study

General Data Protection Regulation

Information about how I (Tracy Mitchell) handle your data is described in the Information Sheet that accompanies this document. The following is additional information, including Edge Hill University's Privacy Notice and the lawful basis for processing your data.

Privacy Notice

At Edge Hill University, we are committed to respecting and protecting your personal information. To find ways in which we use your data or information, please see edgehill.ac.uk/about/legal/privacy.

Lawful Basis for Processing Data

Academic research is conducted in the public interest for current and future generations, so the lawful basis for research data collection is that of a necessary 'public task', so the collection of personal data is 'necessary for the performance of a task (research) carried out for reasons of public interest'.

Health and social care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research. I am registered with the Health and Care Professions Council (HCPC), so must also adhere to their Standards of Conduct, Performance and Ethics.

Transparency

This study is sponsored and funded by Edge Hill University as part of my PhD programme of study. I will be using information from you in order to undertake this study and will act as the data controller for this study. This means that I am responsible for looking after your information and using it properly.

Your personal information and interview data will be stored in my password protected drive on the Edge Hill University encrypted network, which I will also access from my personal (strong) password protected computer at home that uses up-to-date anti-virus and anti-spy software. To safeguard your rights, your personal information (name and contact details and consent form) will not be combined with your interview data (the audio file/s of your interview, your interview transcripts and your photographs, if any). Your personal information will be securely stored separately from your interview data, and your interview transcript and photographs will be stored separately from the audio file/s of your interview.

Audio recordings of your interview will be transferred from the Dictaphone to my university drive as soon as possible after the interview. The audio recording of your interview will be deleted from my university drive at the end of the study (7th September 2020 at the latest).

I will assign a participant code to your interview data, which, once transcribed, will contain the minimum personally-identifiable information possible (i.e. all names and places and any other information that I believe could result in you being identified will be anonymised). As mentioned in the information sheet, I must emphasise that if you have consented for me to use your photographs in my PhD thesis, presentations or publications, people who know you/your family, your home or the equipment could identify that you or someone from your family has taken part in the study. Your interview data will also be stored within my password protected NVivo (QSR) account, which is the software package that I will use to analyse the data.

Once the study has ended, anonymised transcripts and your photos (if any) will be kept on the Edge Hill University encrypted network for at least 10 years. If I leave Edge Hill University employment, I will pass responsibility to Professor Bernie Carter as my Director of Studies for future proofing the data. My supervisory team and regulatory organisations may look at the anonymised interview data, my analysis and findings to check the accuracy of this study, but I will not share your personal information or the audio recording of your interview with anyone, including my supervisory team, unless you disclose any information that suggests that you or others have been harmed or are at risk of harm.

Your anonymised interview transcripts and photographs (if any) and brief anonymised demographic information (i.e. the number of people in your household and the age, gender and birth order of your child/ren) will only be used in my future research studies (which may not be at Edge Hill University), or those of my supervisory team, if you have consented to this.

If you wish to raise a complaint on how I have handled your personal data, you can contact the Data Protection Officer (dataprotection@edgehill.ac.uk) who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Researcher: Tracy Mitchell
Graduate Teaching Assistant/PhD Studentship, Edge Hill University
01695 650960
Tracy.Mitchell@edgehill.ac.uk
Supervisory Team: Professor Bernie Carter, Professor Lucy Bray, Dr Lucy Blake (all from Edge Hill University) and Dr Annette Dickinson (Auckland University of Technology, New Zealand).

Appendix 35: Data analysis node (code) list after 4 participants from 2 families (4.12.18)

Name	Sources	References
CARERS (PAID AND FAMILY)	2	5
Carer skills - health and tech	2	2
Family support	4	12
Training carers	1	1
CHILD	1	1
Behaviour	1	9
Child Health	2	9
Diagnosis	1	3
Lengthy hospital stays	2	2
Prognosis	1	3
Unpredictability	1	1
Mobility	1	3
Therapies	1	1
DEMOGRAPHICS	2	3
Age - Siblings	3	3
Age - TD CYPYA	2	2
Time lived in home	2	2
HOME	1	1
Adaptations to	3	6
Extensions of	3	6
Choice or decision making	2	5
Impact on home	4	24
How rooms or space in the boundaries of home are now used	3	6
Location of technology in the home	1	2
Mobilisation within	4	6
OTHER HOMES OR PLACES e.g. hospital	3	18
Safety	2	12
PROFESSIONALS	0	0
Relationships with professionals or organisations	2	15
Knowing the child		
RECOMMENDATIONS	3	11
TECHNOLOGY	1	3
Acceptance of	1	1
Age equipment introduced	2	3
Anticipating need	3	9
Benefits of	2	7
Cost - awareness of; justification for	1	1
Durability	1	1
Forgotten	1	2
How used	1	1
Identification of appropriate	1	1
IMPACT ON CHILD	2	26
IMPACT ON COUPLE RELATIONSHIPS	1	2
IMPACT ON FAMILY RELATIONSHIPS OR ACTIVITIES	2	6
Impact on going or being out of the home	3	14
IMPACT ON GRANDPARENTS OR OTHER FAMILY MEMBERS	4	15
IMPACT ON PARENT	2	16
Employment	1	2
Financial	1	3
Needing support	1	1

Parent Skills	2	8
Changing public opinion	1	2
Physical	3	8
Practical - e.g. shopping, chores	1	1
Psychological or Emotional	2	8
Constant presence near child	2	3
Used to be	1	1
Sleep	1	3
Social	2	6
Peer support	1	6
Societal reactions	1	3
IMPACT ON SIBLING	2	12
Obstructing view or affecting use of space	1	1
Other adults caring for sibling	1	1
Psychological	2	5
Social	1	3
Supporting care of TD child	2	5
Impact on visitors to the house	1	1
No longer used	2	3
Not supplied	3	8
Ordering of tech or stock	2	3
Delivery of	1	2
Getting rid of cardboard or rubbish	2	2
Problematic	1	5
Resistance to	2	10
Storage of	3	5
Transportability	1	1
Types of or Used for	4	24

Appendix 36: Data analysis node (code) list after 11 participants from 5 families (21.12.18)

Name	Sources	References
CARERS (PAID AND FAMILY)	9	23
Training carers	6	14
Strategy for...	1	1
Carer skills - health and tech	8	20
Family support	9	21
Knowing the child	5	8
Carer safety **or employer responsibilities**	2	4
Accessing carers or babysitters	3	13
Roles	1	1
Balancing family privacy with support	2	6
Caring for carers	1	1
Presence of	2	11
Number of…	1	1
Physical	1	1
Confidence	1	2
Mess	1	2
Behaviour	1	2
CHILD	1	1
Child Health	6	18
Complexity of care	2	6
Coordinated Care or service	3	3
Deterioration	5	10
Diagnosis	2	7
Lengthy hospital stays	2	3
Longer lives and thus larger population	2	2
'Normalised'	2	2
Operations (surgery)	1	2
Prognosis	2	4
Rarity of condition	1	1
Temperature regulation	4	7
Unpredictability **or fragility of life**	3	6
Behaviour	1	9
Mobility	2	4
Therapies	1	1
Making a positive contribution	1	1
DEMOGRAPHICS	7	13
Age – Siblings	8	8
Age – TD CYPYA	4	5
Time lived in home	6	7
Moved to a new house with technology	1	1
Wider family expectations and understanding of situation	4	7
'Good'	1	1
HOME	7	9
Access into	2	4
Adaptations to	10	52
Extensions of	10	26
Knowledge, choice or decision making	7	17
Safety	3	18
Mobilisation within	10	27
Impact on home	10	96
Electricity and power (changed from more electric sockets to account for tech needing to be	4	7

positioned near)		
Furniture or furnishings	2	7
How rooms or space in the boundaries of home are now used	8	32
Missing items	1	1
Space	7	29
Emotional space from children, carers	1	3
Wear and tear	4	10
OTHER HOMES OR PLACES e.g. hospital	10	63
Location of technology in the home	5	28
Preferred place	3	10
Privacy within	4	11
Access into	6	9
Forever home – to move house or not	4	7
Meaning of home	3	8
'Good' house, works, meets needs, loved	3	8
Residential	1	1
Not feeling like own	2	4
Best place for ACP (advance care planning)	1	1
Use of household articles	1	4
Respect or not for home and family of people providing services	1	1
Neighbours	1	2
Neighbourhood	1	1
METHOD	1	2
PROFESSIONALS	0	0
Relationships or **communication** with professionals, **carers** or organisations	8	62
Difficult conversations about palliative care	1	2
Proving or evidence, fighting for services	2	8
Knowing the child	4	11
Skills, knowledge or service	5	40
Knowing the parent(s)	2	5
Caring for parents	1	1
Kant's deontology vs utilitarian approach	1	2
Expectations of parents	2	3
Terminology	2	2
Lack of understanding	1	6
Professionals communication with each other	1	3
RECOMMENDATIONS	8	41
TECHNOLOGY	2	4
Acceptance of	9	25
Adult tech used for children	1	2
Advances in	2	19
Aesthetics	3	5
Age equipment introduced	8	18
Annoying or frustrating	1	7
Anticipating need	6	18
Backgrounded=Good tech	4	11
Benefits of or good tech	9	66
Non-Medical Technology	2	7
Reducing hospitalisation	3	5
Choice **or decision making**	5	17
Cost - awareness of; justification for	4	9
Damage to	1	3
Durability	4	17
Embodied	2	2

Favourite	7	25
Foregrounded	3	3
Forgotten	4	5
Funding for	5	14
How used	5	6
Hygiene	1	1
Identification of appropriate	5	9
IMPACT ON CHILD	6	33
Assessments	2	4
Choice	2	2
Communication	5	10
Education	3	7
Financial	1	3
Identity	2	3
Independence	5	12
Part of a family in a community	1	2
Physical	8	81
Play	1	1
Privacy and dignity **inc. personal care**	4	10
Psychological or emotional	7	20
Safety	6	37
Sensitisation to medication	1	1
Sensory	5	9
Sibling relationships	1	1
Sleep	1	1
Social	7	30
IMPACT ON COUPLE RELATIONSHIPS	6	15
Couple communication and decision making	1	4
IMPACT ON FAMILY RELATIONSHIPS, FUNCTIONING OR ACTIVITIES	8	56
Impact on going or being out of the home	10	66
Exacerbated as child(ren) get older	1	2
IMPACT ON GRANDPARENTS OR OTHER FAMILY MEMBERS	8	34
IMPACT ON PARENT	4	19
Employment	6	14
Support, or not, of employer	2	3
Financial	7	39
Needing support **or reassurance or accessing information**	6	17
Neglecting own health needs	1	3
Parent **Knowledge**, Skills and Resourcefulness	7	41
Changing public opinion	1	3
Knowing the child	4	5
Saving NHS or SC Costs	2	2
Gratitude	2	2
Social Media or Internet	2	3
Training	3	5
Physical	9	70
Getting older	1	2
Practical - ease of use and e.g. shopping, chores	7	63
Prioritising child's needs	4	8
Psychological or Emotional	8	64
Anxiety	2	10
Cliff Edge	3	5
Concerns about the future	3	5
Confidence	1	1

Constant presence near child	4	10
Enmeshed but not	1	1
Expectations	1	1
Getting through, ways of coping	3	17
Gratitude	1	4
Having control	2	4
Identity or role(s)	2	9
Intelligence and thinking	3	3
Live in the moment	2	6
Memory	1	1
Overlooked needs	1	2
Personality	2	4
Altruistic to other parents	1	1
Planning	5	43
Positive attitude inc. lucky or fate	4	15
Pretend reality to protect self and cope in other places	1	1
Raising awareness	2	3
Sensory - see, hear	8	37
Sixth Sense or intuition	2	3
Used to be	2	3
Worry about other people's perceptions	2	5
Relationship, communication or time with child's siblings	3	9
Respite	4	16
Responsibility	2	13
Role	4	6
Sleep **inc. exhaustion**	6	20
Social	8	22
Feeling different to other 'typical' families	2	5
Friends understanding or not	1	6
Isolation	1	5
Leisure	2	6
Peer support	3	10
Societal reactions	3	8
Time	7	50
Routine	2	12
A new normal	1	14
Urgency	2	6
Transition of child into adult services	2	6
Trusting others	5	13
IMPACT ON SIBLING	5	15
Academic Attainment or Educational attendance	3	5
Behaviour	1	1
Financial	1	1
Identity	1	1
Maturity or not	2	4
Mediating with wider family	2	2
Obstructing view or affecting use of space	1	1
Other adults caring for sibling	1	1
Physical	3	5
Play	1	3
Practical	1	9
Privacy	3	4
Psychological	5	17
Fear of medical treatment	1	1
Perceptions of hospital 'space'	1	1

Unachievable hopes and dreams	1	1
Relationship **(inc. communication)** with parent(s)	4	12
Relationship with carers	2	3
Safety	2	5
Sensory	5	7
Skills	1	3
Sleep	1	1
Social	4	11
Support	1	1
Supporting or being involved in care of TD child	6	17
Impact on sibling relationships	5	8
Impact on visitors to the house	5	10
Sensory	1	1
Influx of more	3	13
Least favourite	4	8
Love-hate relationship	2	4
Maintaining, servicing or **cleaning**, wear and tear, **updating**	5	17
No longer used	3	4
Not supplied	10	23
Ordering of tech or stock	6	20
Delivery of	5	13
Getting rid of cardboard or rubbish	5	6
Planning for	3	4
Problematic	5	37
Resistance to	5	14
Risks of	1	1
Size or Weight	2	8
Spare	1	1
Storage of	10	23
Transportability	7	18
Types of, **number** or Used for **(includes operations or medications, not just tech)**	11	153

Appendix 37: Data analysis node (code) list after 17 participants from all 10 families (18.1.19)

Name	Files	References
CARERS (PAID AND FAMILY)	10	24
Accessing carers or babysitters	9	44
Balancing family privacy with support	4	8
Behaviour	1	2
Carer safety or employer responsibilities	5	9
Carer skills - health and tech	11	30
Caring for carers	1	1
Confidence	1	2
Family support	15	27
Knowing the child	7	11
Mess	1	2
Not nurses	1	1
Number of…	1	1
Physical	2	2
Presence of	5	16
Retention	3	6
Roles	3	3
Training carers **inc. recruitment**	10	26
Strategy for...	2	2
CHILD	1	1
Behaviour	5	20
'Good'	1	1
Child Health **and Development**	10	24
Child Knowledge of own condition, how to manage	3	5
Complexity of care	6	13
Coordinated Care or service	4	4
Deterioration	8	15
Diagnosis **inc. assessment**	7	24
Lengthy hospital stays	6	13
Locality of services	5	9
Longer lives and thus larger population	2	2
Medical Appointments	4	4
'Normalised'	3	3
Operations	1	2
Prognosis	4	12
Rarity of condition	2	4
Temperature regulation	4	7
Unpredictability or fragility of life	7	17
Making a positive contribution	1	1
Mobility	2	4
Therapies	1	1
DEMOGRAPHICS	13	20
Age - Siblings	12	13
Age - TD CYPYA	9	11
Moved house with technology	2	4
Time lived in home	11	13
Wider family expectations and understanding of situation	5	8
HOME	9	11
Access into	7	10
Adaptations to	16	78
Best place for ACP	1	1
Extensions of	11	28

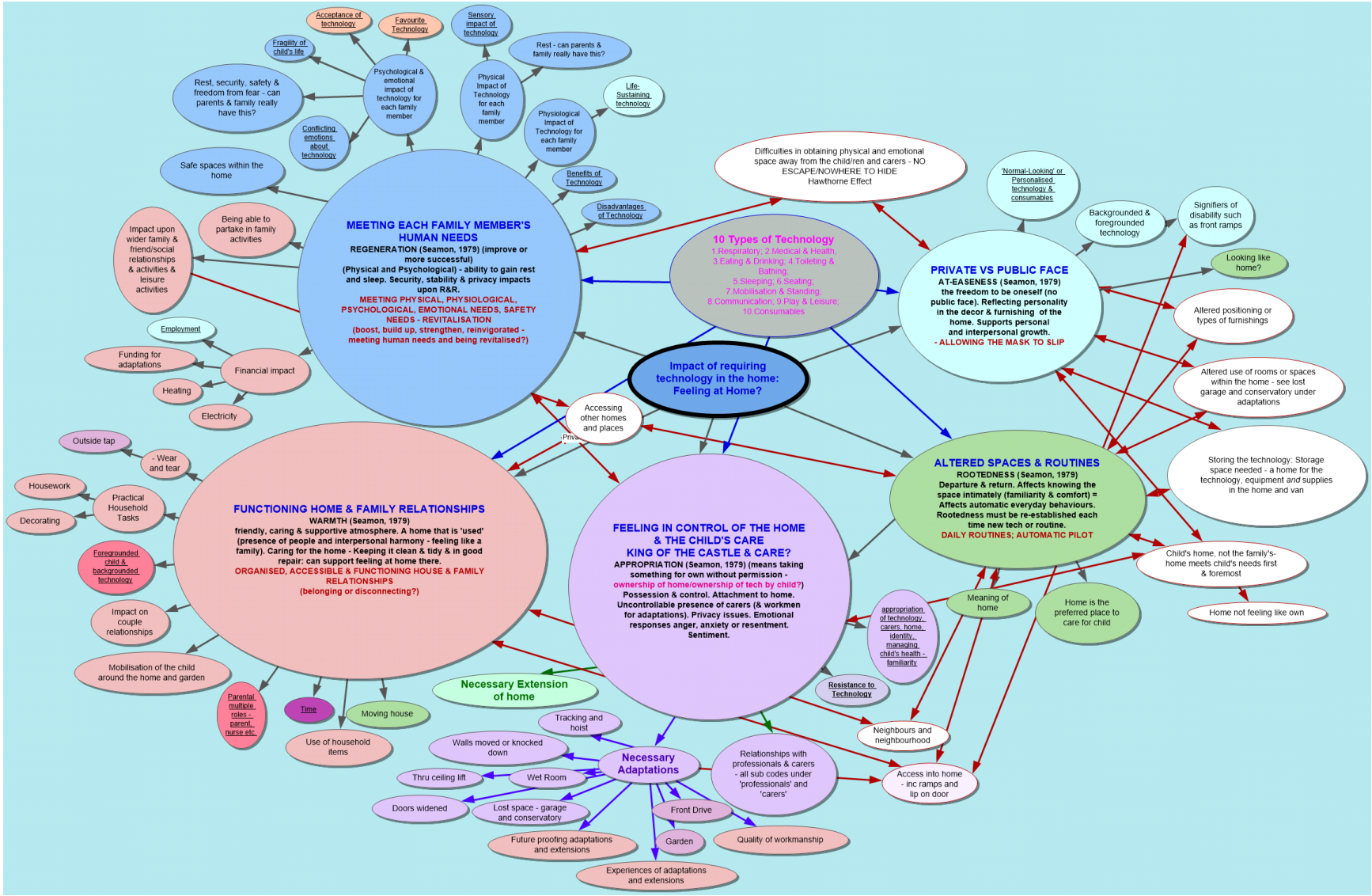
Knowledge, choice or decision making	8	19
Forever home - to move house or not	8	12
'Good' house, works, meets needs, loved	5	10
Impact on home	16	124
Electricity and power	7	13
Furniture or furnishings **inc. decor**	7	18
How rooms or space in the boundaries of home are now used	13	54
Missing items	1	1
SPACE, **includes space in the van etc**	11	56
Emotional space from children, carers	2	4
Wear and tear	6	13
Location of technology in the home	8	42
Meaning of home	4	9
Mobilisation within **home and garden**	16	43
Neighbourhood	2	2
Neighbours	2	3
Not feeling like own	4	9
OTHER HOMES OR PLACES e.g. hospital. Includes **holiday 'spaces'**	16	104
Preferred place	6	14
Privacy within	5	12
Rented	1	1
Residential	1	1
Respect or not for home and family of people providing services	1	1
Safety **and security**	7	24
Use of household articles	3	7
METHOD	1	2
PROFESSIONALS	0	0
Accessing	3	10
Authoritarian - dictating to parents	4	10
Caring for parents	3	3
Expectations of parents	3	5
Kant's deontology vs utilitarian approach	1	2
Knowing the child	8	16
Knowing the parent(s)	3	6
Lack of understanding	3	13
Professionals communication with each other	3	5
Relationships or communication with professionals, carers or organisations	13	105
Difficult conversations about palliative care	1	2
Proving or evidence, **fighting for tech** or services	7	28
Skills, knowledge or service	10	59
Terminology	6	12
RECOMMENDATIONS	14	55
TECHNOLOGY	2	4
Acceptance of	14	43
Access to	4	19
Adult tech used for children	1	2
Advances in	2	19
Aesthetics	7	12
Age equipment introduced	10	22
Anticipating need	8	21
Backgrounded=Good tech	6	15
Benefits of or good tech	15	93
Reducing hospitalisation	5	9

Choice or decision making	10	32
Cost - awareness of; justification for	5	11
Damage to	1	3
Durability **inc. future proofed**	5	20
Embodied	4	5
Favourite	9	27
Foregrounded	4	6
Forgotten	5	18
Funding for **- includes supplied**	10	29
How used	7	8
Hygiene	3	4
Identification of appropriate	5	9
IMPACT ON CHILD	6	33
Assessments	3	6
Choice	3	3
Communication	9	16
Development	2	5
Education	8	17
Financial	1	3
Identity	5	7
Independence	10	27
Part of a family in a community	6	10
Physical **inc. QOL inc. pain**	14	126
Play	5	6
Privacy and dignity inc. personal care	10	21
Proximity of tech to child	2	5
Psychological or emotional	11	25
Relationship with carers	2	4
Safety	9	51
Sensitisation to medication	1	1
Sensory	8	12
Sibling relationships	4	6
Sleep	6	8
Social	13	50
IMPACT ON COUPLE RELATIONSHIPS	9	29
Couple communication and decision making	2	7
IMPACT ON FAMILY RELATIONSHIPS, FUNCTIONING OR ACTIVITIES	13	71
Impact on going or being out of the home	16	98
Exacerbated as child(ren) get older	3	4
IMPACT ON GRANDPARENTS OR OTHER FAMILY MEMBERS	12	42
IMPACT ON PARENT	4	19
Employment	10	22
Support, or not, of employer	4	5
Financial	12	64
Needing support or reassurance or accessing information	8	19
Neglecting own health needs	2	4
Parent Knowledge, Skills and Resourcefulness	12	62
Changing public opinion	1	3
Knowing the child	7	13
Saving NHS or SC Costs	3	3
Gratitude	2	2
Social Media or Internet	2	3
Training	6	9
Physical	15	109
Getting older	3	5

Practical - ease of use, **practical skills** and e.g. shopping, chores	13	96
Prioritising child's needs	6	11
Psychological or Emotional	12	73
Anger, annoyance or frustration	5	15
Anxiety **and depression**	6	23
Assertive - having to become	3	7
Attachment to child	1	2
Cliff Edge	5	7
Commitment to advancing child's ability	2	6
Concerns about the future	7	14
Confidence	3	3
Constant presence near child	8	28
Constant availability	2	4
Constant thinking about child	3	5
Enmeshed but not	2	2
Expectations	1	1
Getting through, ways of coping	8	36
Gratitude	3	6
Having control	4	6
Identity or role(s)	3	10
Intelligence, common sense and thinking	4	4
Live in the moment	3	7
Memory	3	4
Overlooked needs	2	3
Personality	2	4
Altruistic to other parents	3	4
Planning	9	58
Positive attitude inc. lucky or fate	7	19
Pretend reality to protect self and cope in other places	1	1
Privacy	3	3
Raising awareness	2	3
Sense of purpose	1	1
Sensory - see, hear	13	59
Sixth Sense or intuition	3	5
Used to be	3	4
Worry about other people's perceptions	4	7
Relationship, communication or time with child's siblings	4	10
Respite	8	32
Responsibility	3	16
Role	8	12
Sleep inc. exhaustion	11	31
Social	14	32
Feeling different to other 'typical' families	3	6
Friends understanding or not	4	12
Isolation	3	7
Leisure	5	16
Peer support	8	19
Societal reactions	6	13
Time	13	80
Routine	7	25
A new normal	4	19
Urgency	3	8
Transition of child into adult services	4	14
Trusting others	7	17
IMPACT ON SIBLING	6	16
Academic Attainment or Educational attendance	4	6

Behaviour	2	3
Financial	1	1
Identity	1	1
Maturity or not	2	4
Mediating with wider family	2	2
Obstructing view or affecting use of space	1	1
Other adults caring for sibling	2	2
Physical	4	6
Play	2	5
Practical	1	9
Privacy	3	4
Psychological	7	20
Fear of medical treatment	1	1
Perceptions of hospital 'space'	1	1
Unachievable hopes and dreams	1	1
Relationship (inc. communication) with parent(s)	6	16
Relationship with carers	4	6
Safety	2	5
Sensory	8	11
Skills	1	3
Sleep	1	1
Social	6	18
Support	1	1
Supporting or being involved in care of TD child	8	21
Impact on sibling relationships	7	11
Impact on visitors to the house, **having to have visitors**	9	15
Sensory	3	3
Influx of more	8	37
Least favourite	4	8
Love-hate relationship	3	7
Maintaining, servicing or cleaning, wear and tear, updating, **customising**	11	38
Travelling to take tech for servicing or to obtain tech	1	1
No longer used	7	12
Non-Medical Technology (moved here from Benefits of)	6	14
Not supplied	14	35
Ordering of tech or stock	10	35
Delivery of	10	28
Getting rid of cardboard or rubbish	9	13
Planning for	5	6
Problematic	9	56
Resistance to	11	25
Risks of	2	3
Size or Weight	6	21
Spare	4	4
Storage of	14	34
Transportability	9	24
Types of, number or Used for (includes operations or medications, not just tech)	17	241

Appendix 38: Mind Map to Help Identify Themes from the Data



Appendix 39: Example of Second Level Coding

Demographic details
Types of technology
Extension
- Inappropriate
- Future proofing
- Funding

Necessary adaptations to the home
- Wet room
- Tracking and hoist
- Walls moved or knocked down for more space
- Through the ceiling lift
- Doors widened
- Conservatory lost
- Garage lost
- Garden
- Front drive
- Home, access into
- Lip on door
- Outside tap

Location of technology in the home
Impact of technology upon the home
- Impact of having the technology upon space within the home and van
- Moving furniture to enable the child to have easier access
- Mobilisation within the home and garden
- Storage space (a home for the equipment and supplies within the home)
- Altered use of rooms or spaces within the home
- Difficulties in obtaining physical and emotional space away from the child/ren and carers
- Safe spaces within the home
- Electricity
- Heating
- Security
- Spills
- Wear and tear
- Housework
- Decorating
- Insurance
- Use of household articles
- Missing items
- Meaning of home
- Being able to care for child at home – home is preferred place
- Childs home – home is built for child – rather than being a family home
- Home not feeling like own
- Word intrusion used
- Technology alters how home is furnished
- Aesthetics
- Moving house
- Neighbours and neighbourhood
- Inability to access other places – friends and relatives houses, holidays, hospital etc.